Title Page

**Patient and Family Advisory Councils within Healthcare Organizations**

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**Abstract**

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**Patients and Family Advisory Councils within Healthcare Organizations**

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**Abstract**

Patient and Family Advisory Councils (PFACs), are individuals who have received care at your hospital and who offer insights and input to help hospitals provide care and services that are based on patient- and family-identified needs rather than the assumptions of clinicians or other hospital staff about what patients and families want. (AHRQ, 2020) These Councils provide value for patients and families as their impact directly affects organizations’ decisions on providing care. Patient and Family Advisory councils derive from a need to include patient and family advocates in the decision-making process to provide better quality patient-centered care. They are dependent on participation from the community, advocates, and organizational leadership in order to enact change within the system. Utilizing best practices for implementing, operating, and sustaining a Patient and Family Advisory Council is important to their continual success. Although best practices are dependent on measures specific to each healthcare organization, an achievement of best practices can result in positive outcomes to improve patient and family-centered care. Strategies and resources, such as implementation handbooks and guidelines, are available to organizations to overcome challenges in PFAC implementation. Massachusetts’ state mandate requiring healthcare organizations to maintain active PFACs is a useful comparison to benchmark against successful Councils (Patient and Family Advisory Councils, 2009). Patient and Family Advisory Councils are also an instrumental way for healthcare organizations to provide care to the community based on feedback from their consumers. Patient-centered care contributes to the enhance satisfaction and well-being of community members, families, and patients. The public health impact of PFAC initiatives suggest that the utilization of community perspectives by incorporating it into organizational decision-making and operational processes, leads to implementation of patient-centered treatment plans and personalized healthcare.

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# Introduction

Patient and Family Advisory Councils are a group of individuals who have received care at your hospital and who offer insights and input to help hospitals provide care and services that are based on patient- and family-identified needs rather than the assumptions of clinicians or other hospital staff about what patients and families want. (AHRQ, 2020) In the United States, Massachusetts is the only state required by the Department of Public Health to have mandated Patient and Family Advisory Councils (“PFAC”) in hospitals (Health Care for All Massachusetts, 2019). Though not required, healthcare systems and independent organizations across the country are establishing Patient and Family Advisory Councils to create patient, family, and advocacy community partnerships. Due to the lack of regulatory requirements and the uniqueness of each individual healthcare organization, establishing best practices for PFACs that universally meet the needs of all healthcare organizations nationally proves to be a challenge. Healthcare organizations have access to electronic guidelines and PFAC reporting resources and can leverage Massachusetts’s mandated practices to incorporate Patient and Family Advisory Councils into their own institutions. Although there is no centralized system and limited reporting requirements for information sharing, healthcare organizations continue to establish PFACs to increase patient engagement and reinforce the importance of improving quality care.

The purpose of a PFAC is to engage the community a healthcare organization serves in decision making processes and providing feedback. It is through patient experiences that the council members bring their expertise, thoughts, ideas, and opinions. It is a direct way to have patient representation from people who can provide feedback to the organization based on firsthand knowledge. The goal of a PFAC is to enhance patient care and improve quality and safety standards. The value in having patient representation eliminates uncertainty about the patient perspective. Developing a PFAC can bridge the patient-provider divide by eliminating ambiguities surrounding treatment efforts and thus, promoting further coordinated patient and family-care strategies. The value in having an established PFAC is to engage the Council in meaningful and thoughtful discussions. The significance of feedback is ultimately to evoke change on a current, future, or experimental practice to support the continued growth of a healthcare organization.

#  Governance

In 2006, Massachusetts enacted a health reform law supported by Health Care for All (HCFA) that aims to provide comprehensive, affordable, accessible, and culturally competent care to everyone, especially those who are most vulnerable (Wachenheim, 2015). From the enactment of the health reform law stemmed a statewide Consumer Health Quality Council. This council’s objectives were to address aspects of the law that failed to adequately support issues surrounding quality improvement and cost containment. It does so by allowing patients the opportunity to advocate for better-quality care within the Commonwealth. The Council is comprised of patients who have first-hand experience receiving care in the state of Massachusetts. The outcome of the Council was drafting legislation to include implementation of public reporting on infection rates in hospitals, public reporting of the National Quality Forum’s Serious Reportable Events in hospitals, nonpayment for care needed following the occurrence of an SRE, apology and disclosure following unanticipated medical outcomes, and ideas as they pertained to research that had been conducted on PFACs, patient- and family-activated rapid response teams. (Wachenheim, 2015) In the summer of 2008, Massachusetts Senator Timothy Murray’s bill came into law. The outline of the bill mandates that a hospital shall establish a Patient and Family Advisory Council to advise the hospital on matters including, but not limited to, patient and provider relationships, institutional review boards, quality improvement initiatives, and patient education on safety and quality matters to the extent allowed by state and federal law (Patient and Family Advisory Councils, 2009). See Appendix A for the complete legislature.

After the law was introduced, HCFA continued their efforts by supporting the continuation of learning about and development of PFACs. They serve as the centralized hub for all Patient and Family Advisory Council reporting. For the last six years, Health Care for All has published PFAC reports to their website to ensure transparency of PFAC outcomes (Health Care for All Massachusetts, 2019). For consistency and simplicity purposes, HCFA has created a standardized reporting template. All of Massachusetts’s healthcare organizations have access to the template, which serves as a master guide for completing PFAC annual reports. The sections include, but are not limited to; general information, i.e. organizational contacts and leadership, PFAC organization membership, community representation demographics, PFAC operations metrics, orientation and continuing education, and PFAC impact and accomplishments. Each section contains a subset of guidelines suggested for completion. There are options for selecting pre-determined responses as it pertains to generalized information and explanatory sections for in-depth elaboration on Council practices and progress. Although this template serves as a useful resource for most healthcare organizations, no organization is required to use this format. Alternative renditions of finalized reports can be submitted, as it is still a requirement by law to provide HCFA with an annual report. This type of publicized transparency lends itself to outside organizations wanting to learn and implement strategies within their own institution.

# Organizational Structure

Patient and Family Advisory Councils are a unique entity within a health care organization, and no two Councils are the same. As the goals and needs differ vastly from system to system, the organizational structure of each PFAC will in turn be different. Even PFACs within the same organizational healthcare system can have contrasting goals.

Factors that define the patient population of a hospital are established by a series of environmental determinants. Hospitals and healthcare facilities have different functionality, size, location, ownership, and specialization. Functionality is a term used to categorize healthcare institutions based on the relevance of services they provide. Please see Appendix B for specifics on the Hospital and Healthcare Facility classifications.

Size is a measure of how many beds are within the facility. Hospitals can be categorized by the following;

Small hospital - Less than 100 beds

Medium hospital – between 100 and 499 beds

Large hospital – more than 500 beds

(Gallagher Healthcare, 2018)

Location is a classification that determines whether a hospital is located in a rural or urban area. Rural area hospitals tend to have limited resources and serve smaller populations. Urban hospitals serve larger more diversified populations and have greater access to resources.

Ownership of a healthcare organization is a determinant of Patient and Family Advisory Councils. Depending on the type of institution, for-profit, non-profit, private, or public, the motivation of PFAC initiatives will be driven by the decisions of the organizational leadership.

Institutions with a primary focus on specializations require recruitment for the PFAC from a targeted group of individuals. Specialties are areas of expertise based on the hospital or the physicians that practice there. Specialties innately narrow the scope of practice. The consumers will be patients having a particular skill or niche market that will define the patient population of that organization.

## Specialized Healthcare Center vs. Regional Hospital

Based on structural contingency theory, it is evident that the composition of Patient and Family Advisory Councils is dependent on the diversity of the community. Healthcare organizations are not universally designed, nor is any one community identical to another. Therefore, having one organizational design will fail to accommodate each individualized institution. The ambiguity of the environment will drive the configuration of the organization's goals. Each PFAC will differ vastly in demographics, age, race, gender, socio-economic status, education level, etc. Due to the population of patients an organization serves, it is important to have the PFAC members represent similar types of individuals. In determining the goals of the PFAC, it is important to understand the constructs around forming a PFAC. In a comparative analysis of a specialized treatment center and a regional hospital, there are many differences in the dynamics that factor into establishing appropriate representation of their PFAC membership.

## Specialized Healthcare Center Analysis

Dana-Farber Cancer Institute is a non-profit organization, founded in 1947 and is located in Boston’s dense metropolitan area. The institute serves both adult and pediatric patients. For this reason, they have two separate Patient and Family Advisory Councils. Each of the two PFAC’s run autonomously to one another. Dana-Farber Cancer Institute is a 30-bed facility, primarily focusing on outpatient treatments. Dana-Farber Cancer Institute, reported in 2019 as having over 640,000 annual outpatient visits. In addition to their consumer base in downtown Boston, they serve a diverse range of patients from the state of Massachusetts and internationally. Their mission is:

 “The mission of Dana-Farber Cancer Institute is to provide expert, compassionate care to children and adults with cancer while advancing the understanding, diagnosis, treatment, cure, and prevention of cancer and related diseases. As an affiliate of Harvard Medical School and a Comprehensive Cancer Center designated by the National Cancer Institute, the Institute also provides training for new generations of physicians and scientists, designs programs that promote public health particularly among high-risk and underserved populations, and disseminates innovative patient therapies and scientific discoveries to our target community across the United States and throughout the world.”, (Dana-Farber Cancer Institute, 2020).

As reported in 2019, Dana-Farber's two Patient and Family Advisory Councils focused their efforts on goals that support the mission of the organization. Examples of initiatives from both the Adult and Pediatric PFAC’s were improvement and re-design of PFAC’s bylaws and policies. This included an improvement to the goal-setting process and mapping of goals to align with the institution's goals. Although a comparison of the adult and pediatric PFAC’s indicate parallel initiatives, each Council has separate goals and objectives, as see in table 1.

Table 1 Dana-Farber Cancer Institute’s Patient and Family Advisory Councils’ Goals & Objectives, FY 2019

|  |
| --- |
| **Dana-Farber Cancer Institute’s Patient and Family Advisory Councils’** **Goals & Objectives, FY 2019** |
| *Pediatric Patient and Family Advisory Council* | *Adult Patient and Family Advisory Council* |
| * Build a learning relationship with Boston Children’s Hospital Family Advisory Councils
 | * Support and implement initiatives aimed at the growth of patients nationally and internationally
 |
| * Increase engagement and accountability of PFAC members and PFAC staff
 | * Deepen the patient and family centered experience at the institute
 |
| * Create transition plans for long standing members and proactively recruit new members
 | * Support new marketing, branding, and development strategies
 |

Additionally, the pediatric and adult PFAC members participated in the re-designation of the Magnet process and site-visit, along with the development and launching of the Jimmy Fund Clinic rounding program. Continually, Dana-Farber's PFAC’s work to engage patients and families in these Councils by developing innovative ways to promote participation remotely to accommodate those who have extensive and demanding treatment plans.

## Regional Hospital Analysis

Cooley Dickinson Hospital is a 140 bed, non-profit organization that was founded in 1885, and is located in Pioneer Valley, a rural area of Northampton, MA. According to the United States census, in 2018, the population of Northampton was 28,726. At that time 87.9% of the population was reported Caucasian. Of the area's population, 56.7% were females between the ages of 19-64. According to Cooley Dickinson’s 2018 fiscal year reporting, they served 78,992 community members and had 6,538 inpatients. Their mission is:

“To serve our patients and communities with exceptional, compassionate, and

personalized care.”, (Cooley Dickinson Health Care, 2020)

In conjunction with the U.S. census data, Cooley Dickinson indicated in the 2019 PFAC report, 100% of the patient and family advisors were Caucasian. However, over the last year, this PFAC recorded having received diversity training on implicit bias. Notable accomplishments from last year’s goals were providing feedback on a new inpatient menu, reviewing patient portal enrollment materials, welcome packages, and messaging for appointment reminders, and reviewing palliative care, diabetes, and language assistance programs. In an effort to diversify the PFAC and recruit new members, Colley Dickinson has reached out to community groups in addition to their Language Assistance department for referrals of potential candidates.

# Goal Setting

In any organization, goal setting is crucial for continual growth and development. The process of establishing goals is important for Patient and Family Advisory Councils for a number of reasons. As community members advocate for improvements of patient-centered care, it is helpful to define and ensure understanding of objectives to set clear intentions. The opinions and feedback across individuals may vary; however, having clearly defined goals can help navigate the path to making necessary change (AHRQ, 2020).

Goals are best set by creating an outline of targets to accomplish. This can be done by establishing an agenda to guide Council meetings. The agenda should cover topics aimed at these targets. Agendas can be developed by the organization, from input of the Council members, or a combination of both. Polling both the organization and the Council allows equal opportunity to discuss topics that are valued within each of the groups. Having agendas that support patients and the organization reinforce the intention to provide patient-centered care. PFACs are assets to organizations to help reach goals as they provide guidance from the patient perspective. Defining meaningful goals to create a better patient-centered experience may be the greatest challenge to successful implementation.

According to “Hospitals in Pursuit of Excellence” when orienting the Council, the topic of goals and objectives should be outlined and described to include; progress, measures for success, any priority shifts, and strategic objectives (HPOE, 2013). The figure included below recommends these metrics for tracking the effectiveness of patient and family advisory Councils;



Figure 1 Metrics for Tracking Effectiveness

# Challenges and Best Practices

Patient and Family Advisory Councils face a multitude of challenges from both institutional and community viewpoints. Major challenges healthcare organizations face today include community engagement, governance support, and meaningful outcome reporting. For Patient and Family Advisory Councils to be successful, necessary resources, including ways to select Council members, meeting support, and funding, must be available.

## Community Engagement

In order to become a member of a PFAC, a patient or family advocate must have received treatment at that facility. This is to eliminate any potential conflict of interest and that the interest of the patient is focused on experience with the organization. Organizations have several opportunities to recruit members to apply to their PFACs. Self-nomination or referrals are the most commonly observed ways in obtaining memberships. However, organizations must be cautious that participants act in the best interest of the organization. Not every person who applies to be a PFAC member, will in fact be a valued asset to the Council. A diligent vetting process should be in place to ensure that the goals of a patient advocate match with those of the organization. Efforts to take when establishing the PFAC members should be; phone or in-person interviews, understanding their motivation and intentions, and confirming their availability to contribute to PFAC meetings. Onboarding PFAC members can be timely and costly to an organization. Limiting turnover rates by enlisting members who can remain active during their appointment and uphold the term commitment will be imperative to running a dependable Council.

## Community Engagement Best Practices

The best composition of PFAC members and identifying good candidates is to consider seeking those who have:

1. Familiarity and experience with the practice (as a patient or a family caregiver)
2. Representative of the population most impacted by the care changes being sought
3. Willingness to speak up
4. History of providing constructive feedback to the practice
5. Able and interested in devoting time and energy to working with the practice

(National Partnership for Women & Families, 2013)

Although the National Partnership for Women & Families have identified characteristics that lead to the selection of ideal candidates for PFAC’s, there is still a great variability surrounding the composition of healthcare organization’s needs and how they determine Council members. The best practices are a guideline for other healthcare organizations to mimic in their own hospital to ensure they have a Council to address their specific healthcare needs.

## Governing Bodies

A common challenge faced by healthcare organizations in developing a Patient and Family Advisory Council is the lack of government regulation. Although Massachusetts has established laws that outline certain criteria for PFACs, the law contains obscure language. The criteria outlined in the law are not clearly definable. As it pertains to each organization, the interpretation of the law may differ, which is why no PFACs are identical. Massachusetts has the benefit of a centralized organization, Health Care for All, that serves as a hub for the continual maintenance and enforcement of the PFAC reporting mandate. Health Care for All provides access to resources for health care organization’s ongoing commitment to providing patient-centered care. Health Care for All also publicizes each organization’s annual PFAC report to foster collaboration across organizations who have successfully implemented processes and programs with a patient focus (Health Care for All Massachusetts, 2019). The shared reporting allows leaders in the healthcare industry to make necessary improvements by putting patients first. Authoritative associations, such as the Department of Public Health for the Commonwealth of Massachusetts, are required to hold healthcare organizations accountable for having a PFAC. By law, the government agencies enforce the PFAC mandates to ensure sustainability and compliance. Additionally, authoritative associations administer support for establishing a PFAC, provide resources for ongoing Council efforts, and promote impactful initiatives of successful healthcare organization practices. Having this type of accountability measure is instrumental in forcing organizations to create a PFAC, enlist patient participation, and report on substantive outcomes of community engagement.

## Reporting

Due in part to having only one state with a PFAC mandate, the information available on PFAC outcomes of Massachusetts is scarce. Massachusetts institutions annually present a report highlighting goals, challenges, and reported outcomes of Council initiatives. Despite health care organizations having PFACs across the country, no reporting guidelines or regulations are required. Depending on the organization, it is the determination of leadership and PFACs on how they report their outcomes, if at all. When analyzing data, it is hard for similar organizations to leverage this information, as it is not always made public. As seen in Massachusetts, one of Health Care for All’s goals is to allow institutions to leverage the reports for learning and implementing successful practices (Health Care for All Massachusetts, 2019). It is with this information that health care organizations can use evidence-based data to influence internal change. It is to the advantage of health care organizations, striving to incorporate more patient-centered care to evaluate the reports. It is problematic to limit the amount of reporting to that of one state when outcome data could be reported nationwide.

# Conclusion

Today the topic of healthcare has become one of popular interest among consumers, providers, and politicians. On a grand scale, there are opposing public opinions and tensions among government officials that make for an unclear future as to what policies and procedures surrounding healthcare will look like. Regulations and mandates are only a piece of what healthcare leaders face day-to-day. However, as patients become more aware of their healthcare needs and rely on organizations to meet high quality standards, it is imperative to lean on the perspective of patient experience for institutional decision-making. It is far too common that healthcare organizations base decisions on financial and systematic needs, without properly assessing the implications those decisions will have on patients and quality care. Enhancing organizational awareness to focus on patient-centered care increases the opportunity to make informed decisions around meaningful treatment efforts. It is with the help of the community that organizations make strides every day to improve, coordinate, and integrate patient-centered care into their practices. A healthcare organization can showcase their commitment to serve the community by incorporating their patients in decision-making efforts. The proper utilization of Patient and Family Advisory Councils will likely result in increased patient satisfaction, improved quality, and promote effective patient-centered care initiatives.

* + - * 1. The Commonwealth of Massachusetts’ Legislature of Mandatory Patient and Family Advisory Councils for Hospital Licensure

The Commonwealth of Massachusetts’ Legislature of Mandatory Patient and Family Advisory Councils for Hospital Licensure

105 CMR 130.1800: Patient and Family Advisory Council

(A) A hospital shall establish a Patient and Family Advisory Council to advise the hospital on matters including, but not limited to, patient and provider relationships, institutional review boards, quality improvement initiatives, and patient education on safety and quality matters to the extent allowed by state and federal law.

(1) A hospital shall establish a Council no later than October 1, 2010.

(2) No later than September 30, 2009, a hospital shall prepare a written report outlining the hospital’s plan to establish a Council by October 1, 2010.

(3) No later than October 1, 2010 and annually thereafter, a hospital shall prepare a

written report documenting the hospital’s compliance with 105 CMR 130.1800 and

130.1801 and describing the Council’s accomplishments during the preceding year.

(4) The hospital shall make the reports required in 105 CMR 130.1800(A)(2) & (3) publicly available through electronic or other means, and to the Department upon request.

130.1801: Policies and Procedures for Patient and Family Advisory Council

(A) A hospital shall develop and implement written policies and procedures for the Council, which shall address, at a minimum, the following:

(1) The Council’s purposes and goals.

(2) Membership of the Council including qualifications, selection, retention, term of service, and duties and election of officers. The Department recommends that the chair or co-chairs be current or former patient(s) or family member(s), or a staff person and a patient or family member.

(3) Orientation, training and continuing education for members of the Council.

(4) Roles of members of the Council, which may include the following as examples:

(a) participation on hospital committees, task forces and/or advisory boards;

(b) review of publicly-reported quality information;

(c) participation on committees addressing patient safety issues;

(d) participation on search committees and in the hiring of new hospital staff;

(e) participation in reward and recognition programs;

(f) as co-trainers for clinical and nonclinical staff, in-service programs, and health professional trainees; and

(g) any other role in accordance with the hospital’s policies and procedures.

(5) Responsibilities of members of the Council, including policies that address

confidentiality of patient information.

(B) Required policies and procedures.

(1) The Council shall meet at least quarterly.

(2) Minutes of Council meetings shall be maintained for a minimum of five years.

(3) Minutes of Council meetings including Council accomplishments shall be transmitted to the hospital’s governing body.

(4) At least 50% of the Council members shall be current or former patients or family

members and should be representative of the community served by the hospital.

(Patient and Family Advisory Councils, 2009)

* + - * 1. Hospital Types

Hospital Types

Academic Medical Centers, Acute care, Ambulatory Surgery Centers, Addiction/substance abuse treatment, Community or General, Pediatric, Geriatric, Federal, Rural, Urban, Long-Term Care, Psychiatric, Rehabilitation, Specialty, or Teaching. (Hospital Types, 2020)

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