

# Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals

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Prepared by



INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®





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# Acknowledgments

## INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE (IPFCC)

Founded in 1992 as a nonprofit organization, the **Institute for Patient- and Family-Centered Care** (IPFCC) provides national and international leadership for advancing the understanding and practice of patient- and family-centered care in all settings where individuals and families receive health care and support. Patient- and family-centered care redefines the relationships among patients, families, and health care professionals to create mutually beneficial partnerships. It encourages the sharing of information candidly and supportively and fosters the active participation of patients and families in caregiving and decision-making. IPFCC promotes partnerships among patients, families, community members, and health care professionals to enhance health care policy and program planning and implementation; research and evaluation; quality and safety initiatives; and health care professional education.

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# Executive Summary

## BRIEF HISTORY OF PFACS AND PFAS

In recent years, there have been important shifts in health care. The language and concepts of patient partnership, engagement, and empowerment are being used more frequently in discussions at the national policy level. Patients and families are encouraged to become informed consumers and use data related to patient experience to make choices about their health care. Federal- and state-level initiatives are encouraging health care organizations to create ways for patients and families to collaborate with health care professionals in improving health care policies and practices. Despite this growing recognition of the need for hospitals and health systems to partner authentically with patients and families in care and care improvements, there is a dearth of literature describing the prevalence and functioning of Patient and Family Advisory Councils (PFACs)<sup>1</sup> and other mechanisms for partnering with patient and family advisors (PFAs)<sup>2</sup>.

“Consumers need a lasting and meaningful seat at the table in order to drive and inform health care delivery.”

—*Sharrie McIntosh, Vice President for Programs, NYSHealth*

Recognizing that hospital PFACs are an important way to engage patients and families, the New York State Health Foundation (NYSHealth) funded the Institute for Patient- and Family-Centered Care (IPFCC) to conduct a research study to look at the prevalence and functioning of PFACs in New York State. The findings and recommendations shared in this report offer guidance about supporting and strengthening PFACs not only in New York State but across the United States and beyond.

## PROJECT PURPOSE AND GOALS

The purpose of this project is to address gaps in knowledge about PFAC best practices. Specifically, the project aims to:

1. Determine the prevalence of hospital-based PFACs in New York State;
2. Document variation in hospital-based PFACs within New York State, including identifying differences in characteristics such as composition, structure, resources, management, and functioning;

<sup>1</sup> A formal group that meets regularly for active collaboration among hospital leaders, clinicians, staff, and patient and family advisors on policy and program decisions.

<sup>2</sup> Patients and families who work together with health care professionals to improve health care. Advisors share their insights and perspectives about the experience of care and offer suggestions for change and improvement. Advisors may serve on hospital PFACs and/or other committees, task forces, and groups.



## Executive Summary (continued)

3. Assess the extent to which differences in hospital-based PFAC characteristics are related to selected outcomes, including safety and patient experience of care;
4. Identify best practices for PFACs; and
5. Recommend policy and practice changes for New York State to facilitate the spread of effective PFACs and PFA roles in hospitals.

### DATA COLLECTION

The project consisted of three data collection activities:

1. An online survey of acute care hospitals across New York State to identify the prevalence of PFACs, describe PFAC characteristics, and identify key elements of high-performing PFACs.
2. Key informant interviews with individuals in states that have initiatives to increase the adoption of PFACs.
3. Follow-up interviews and site visits with selected online survey respondents to identify factors that affect the development and sustainability of PFACs.

### KEY FINDINGS

#### Prevalence of PFACs

- Of the 110 New York State hospitals that responded to the survey, 59% currently have a PFAC. There appears to be continued momentum in this area, with another 12% of hospitals reporting that they have a PFAC in development.
- Hospitals with PFACs tended to have slightly younger patient populations and were less likely to be in a rural county, but otherwise were similar to hospitals without PFACs.

#### PFAC Characteristics

Results indicate both strengths and opportunities for improvement related to the adoption and implementation of PFAC best practices.

- Only 29% of hospitals had high-performing PFACs, defined in terms of the PFAC's influence on hospital leadership, strategies, and operations. High-performing PFACs were more likely to provide orientation and training; integrate PFAs into other committees; and evaluate their efforts.



## Executive Summary (continued)

- Among hospitals that reported having a PFAC, there is widespread variation in the implementation of known best practices related to PFAC composition, structure, resources, management, and functioning.
- PFACs develop over time, with progress marked by small—but significant—milestones and continued attention paid to relationship- and trust-building.

### Association with Patient Experience of Care and Safety Outcomes

- Hospitals with high-performing PFACs had significantly higher Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) scores in terms of patients' likelihood to recommend, although lower-performing PFACs also performed better than hospitals with no PFAC (high-performing=87%, lower-performing=86.3%, No PFAC=83.5%,  $p<.05$ ).
- With regard to performance on Centers for Medicare & Medicaid Services (CMS) quality and safety metrics, hospitals with high-performing PFACs had lower rates of pressure ulcers ( $p<.05$ ), sepsis and septic shock ( $p<.01$ ), and 30-day hospital-wide readmissions ( $p<.01$ ) than hospitals with lower-performing PFACs. However, hospitals with a PFAC, regardless of whether it was high- or lower-performing, performed better than hospitals without a PFAC.

### Facilitators for Initiating and Sustaining PFACs

The follow-up interviews and site visits conducted with survey respondents identified certain key facilitators for initiating and maintaining effective PFACs:

- Leadership commitment;
- Staff and clinician buy-in and participation;
- Connection of the PFAC work to broader organizational priorities and growth;
- Realistic expectations coupled with the ability to adapt and respond to challenges; and
- Presence of a culture of patient- and family-centered care and partnership.

### PFAC Best Practices

Overall, the project results verify the importance of certain best practices employed by exemplary PFACs and also show variation in hospital-based PFACs within New York State in terms of adoption of those practices.



## Executive Summary (continued)

### EXEMPLARY PFACS—BEST PRACTICES

#### PFAC structure and membership

- The PFAC has an executive sponsor and staff liaison.
- There is a defined relationship between the PFAC and the hospital/health system leadership and board of directors.
- More than 50% of PFAC members are PFAs; PFAs are representative of the patient populations served.

#### Recruitment

- Recruitment is an ongoing program rather than a one-time event.
- Recruitment strategies are designed to ensure that the PFAs reflect the diversity of communities served.
- Clinicians and staff members help identify potential PFAs; other contacts and resources available through the hospital are used (e.g., support groups, relationships with community organizations).

#### Onboarding and orientation

- Onboarding and orientation are provided to all PFAC members, covering the key elements of the role of a PFA and helping orient PFAs to hospital quality and safety work.

#### PFAC operations

- The PFAC meets regularly, approximately 10 times per year.
- There is an agenda for each PFAC meeting, ideally developed by a PFA chair or co-chair, or by the PFAC.
- Language/translation services, childcare, parking/transportation, and even stipends are provided to encourage participation, especially among disadvantaged populations.

#### Opportunities offered to PFAs

- The hospital offers a variety of ways to serve as PFAs, including virtual opportunities and full membership on key committees, quality improvement and safety teams, and governing boards.

#### Feedback, evaluation, and reporting

- PFAs receive feedback about the impact of their work.
- There is an annual PFAC evaluation that measures the outcomes and impact of PFAC activities and initiatives.
- An annual report is prepared to summarize PFAC accomplishments and future plans and shared broadly with the health system and the community.

## RECOMMENDATIONS

### Strengthening the Involvement of PFAs in Hospitals in New York State

Our recommendations highlight the need to increase awareness about the impact of involving PFAs within hospitals and health systems and about the elements that are integral to high-performing PFACs. Additionally, the recommendations offer strategies for providing support, at many levels, to New York State hospitals so that PFAC development is grounded in best practices and can occur more effectively and efficiently.



## Executive Summary (continued)

Below are five recommendations and suggested opportunities for implementation for the State, hospital associations and systems, foundations, and other stakeholders to consider:

### **1. Build partnerships with patients and families into State and regional quality and safety initiatives.**

- Identify New York State programs and initiatives that would benefit from PFA involvement and determine how partnerships with patients and families could be built into the work;
- Ensure that partnerships with patients and families are a component of State and regional demonstration projects;
- Encourage other key agencies or other stakeholders in the State to model and create incentives for partnerships with PFAs;
- Develop training and education programs to identify and prepare experienced PFAs for participation in State and regional initiatives; and
- Review emerging evidence about the impact of patient/family engagement on the quality, safety, and experience of care, as well as explore specific opportunities for strengthening that engagement.

### **2. Create opportunities for shared learning and mentorship around PFAC work.**

- Collect and share voluntary annual reports from New York State hospital PFACs;
- Support PFAC-to-PFAC mentorships;
- Provide train-the-trainer sessions preparing staff members and PFAs from hospitals with high-performing PFACs to share their expertise;
- Conduct regional or State-level learning sessions about PFACs;
- Establish virtual learning communities dedicated to New York State PFAC development and advancement;
- Create mentorship programs geared toward hospital executives and members of boards of trustees; and
- Provide incentives to support hospitals in documenting and publishing the results and impact of their PFAC work.



## Executive Summary (continued)

### **3. Develop guidance to help hospitals access existing PFAC training resources in ways that address the need for tailored information.**

- Create a roadmap to help hospitals understand the process and evolution of developing partnerships with PFAs;
- Develop self-assessment tools to help hospitals understand where they are in the process of developing those partnerships; and
- Develop an online catalog of existing resources, categorized by (1) level of PFAC development and (2) common issues or challenges.

### **4. Conduct additional research about the evolution and impact of PFACs and expand work to other states and settings.**

Potential areas for research include:

- Building blocks or stages in PFAC development;
- Progression from lower-performing PFACs to high-performing ones;
- Mechanisms by which PFACs influence hospital leadership, strategy, operations, and outcomes;
- Potential causal pathways between the presence and quality of a PFAC and improved hospital performance; and
- Impact of partnerships on PFAs themselves.

### **5. Disseminate PFAC study results to share learnings within and outside of New York State.**

Potential audiences include:

- National and state-level policymakers;
- Private and public insurers;
- Hospital associations;
- Consumer advocacy groups; and
- Hospital leaders, staff, and PFAs.



## Executive Summary (continued)

### CONCLUSION

Hospital PFACs are an effective way to engage patients and families, giving consumers a meaningful seat at the table in health care delivery. By describing the landscape of PFACs in New York State hospitals—their prevalence as well as variations in characteristics—this research study furthers our knowledge about this important mechanism for partnering with patients and families in improvement and change. The study begins needed exploration of PFAC performance and the impact of PFACs not only on hospital strategy and operations but also on the quality and safety of care. The study also confirms and augments prior knowledge about best practices for PFACs.

“Knowing the advantages and benefits of a PFAC has given us all energy. It became our Action Committee’s work and not just my work. Now it’s not a duty or task, but instead a passion.”

—*Director of Quality Critical Access Hospital*

Sharing this research is a critical first step in expanding and strengthening PFACs in New York State. However, if PFACs are to develop more broadly and effectively, the commitment to provide support is needed at the organizational, State, and regional levels. The research study identifies and recommends a number of strategies for these efforts.

Although the research study was conducted in New York State, many of its findings related to PFAC best practices and impact have broader application beyond the Empire State.



# Background

## BRIEF HISTORY OF PFACS AND PFAS

The Institute for Patient- and Family-Centered Care (IPFCC) and other health care organizations have been working for years to bring the voice of patients and families into health care at every level—from the bedside to the boardroom. As a result, there are now some important shifts in the field. The language and concepts of patient partnership, engagement, and empowerment are included more frequently in health care discussions at state and national policy levels. Scores for patient experience of care at hospitals are now consistently documented and publicly reported. Patients and families are encouraged to become informed consumers and use this data to make choices about their health care.

“The only way to ensure value is to talk to the recipients who will be affected by a decision or program. I definitely don’t know what patients and families want. But it’s easy to find out; you just have to ask!”

—Hospital CEO

Federal initiatives are also encouraging hospitals to create ways for patients and families to collaborate with health care professionals in improving health care policies and practices. Since 2012, the Partnership for Patients initiative funded by the Centers for Medicare & Medicaid Services (CMS) has set expectations for Person and Family Engagement (PFE) within the Hospital Improvement Innovation Networks (HIINs), formerly referred to as Hospital Engagement Networks. These expectations include metrics related to discussing patient and family partnership roles at the beginning of a hospital stay; reinforcing these roles at the bedside in care and care planning; and collaborating at the programmatic level, including creating opportunities for patients and families to participate on hospital committees and governing/leadership boards.

At the state level, the same shift toward greater partnership with patients and families is occurring, particularly related to collaboration at the organizational level. For example, Health Care For All and its Consumer Health Quality Council in Massachusetts successfully advocated for the first legislation requiring all hospitals within the state to establish Patient and Family Advisory Councils<sup>3</sup> (PFACs) to work with hospitals on improving care and the care experience. The North Carolina Quality Center is facilitating the development of PFACs in all

<sup>3</sup> A formal group that meets regularly for active collaboration among hospital leaders, clinicians, staff, and patient and family advisors on policy and program decisions.



## Background (continued)

hospitals within the state. Currently, it is estimated that 80% of North Carolina hospitals have PFACs or active Patient and Family Advisors (PFAs).<sup>4</sup>

Despite this growing recognition of the need for hospitals and health systems to partner authentically with patients and families in care and care improvements, there is a dearth of literature describing the prevalence of PFACs and other mechanisms for the involvement of PFAs. Further, there are very few studies describing effective characteristics and functions of PFACs and evaluating the impact of PFACs. There is, however, evidence of widespread variation in the implementation of PFACs, with differences in composition; orientation; support; frequency of meetings; and integration into and influence over an organization's policies, strategies, and operations. These differences appear to have some association with the efficacy of PFACs. For example, hospitals with PFACs that have patients and family members as a majority of their membership, meet at least quarterly, and are hospital-wide report significantly higher patient experience scores than hospitals with PFACs that lack those characteristics.<sup>5</sup>

Individually, hospitals often document the impact of PFACs through quality improvement projects and not through systematic study. Typically, data are tracked inconsistently, for a short period, or in individual units related to a specific project. Results do not get written up and published widely. Without good information describing PFA roles and the structure, components, and functioning of PFACs and their impact on a hospital, as leadership changes or an organization's priorities shift, these collaborative roles for patients and families may not be seen as essential. As a result, the attention to and resources for advisory programs are often reduced.

### GOALS AND SCOPE OF PROJECT

The purpose of this project is to address gaps in knowledge about PFAC best practices. Specifically, the project aims to:

1. Determine the prevalence of hospital-based PFACs in New York State.
2. Document variation in hospital-based PFACs within New York State, including identifying differences in characteristics such as composition, structure, resources, management, and functioning.

<sup>4</sup> Patients and families who work together with health care professionals to improve health care. Advisors share their insights and perspectives about the experience of care and offer suggestions for change and improvement. Advisors may serve on hospital PFACs and/or other committees, task forces, and groups.

<sup>5</sup> Herrin J., Harris K.G., Kenward K., et al. Patient and family engagement: a survey of US hospital practices. *BMJ Quality and Safety*, 2016;25:182–189.



## Background (continued)

3. Assess the extent to which differences in hospital-based PFAC characteristics are related to selected outcomes, including safety and patient experience of care.
4. Identify best practices for PFACs.
5. Recommend policy and practice changes for New York State to facilitate the spread of effective PFACs and PFA roles in hospitals.

“This landmark study describes, for the first time, the landscape of PFACs in New York—how many there are, and how they vary in composition, resources, and role. Most importantly, the project begins to describe best practices for how PFACs can be used as an effective vehicle for actively engaging patients and families in their own health and health care.” —*Sharrie McIntosh, Vice President for Programs, NYSHealth*



# Project Methods

The project consisted of three primary data collection activities:

1. An online survey to describe the prevalence, composition, and functioning of PFACs in acute care hospitals in New York State.
2. Key informant interviews with individuals in states with initiatives to increase the adoption of hospital-based PFACs.
3. Follow-up interviews and site visits with selected survey respondents to identify factors that affect the development, impact, and sustainability of PFACs.

Throughout the project, a 10-member Project Advisory Committee (PAC) comprising PFAs; hospital leaders and staff; New York State organizations and health systems; and individuals from states with initiatives that support the creation of hospital PFACs provided input and guidance. The PAC met five times at key junctures over the course of the project, discussing development of the statewide survey; interview protocols; plans for site visits; survey data analysis and findings; and recommendations resulting from the project.<sup>6</sup> New York State Health Foundation (NYSHealth) staff also participated in PAC meetings.

## ONLINE SURVEY OF NEW YORK STATE HOSPITALS

### Survey Design and Administration

The project team conducted an online survey to identify the prevalence of PFACs among acute care hospitals in New York State, describe PFAC characteristics, and identify key elements of high-performing PFACs. The online survey was drafted based on a review of existing instruments and input from the PAC. The project team piloted the survey with patient experience staff and PFAs from hospitals outside of New York State, and revised items based on their feedback. The final survey contained 54 multiple choice and 14 open-ended questions. Initial questions asked whether hospitals had a PFAC in existence or in development at the unit level. If so, subsequent questions were asked about PFAC best practices, including:

- **Structure:** Elements in place to guide the PFAC's structure and functioning, such as a charter, annual budget, or written goals.
- **Operations:** Operational procedures related to PFAC meetings (e.g., presence of a guiding agenda for meetings, whether the agenda is developed in collaboration with PFAs).

<sup>6</sup> Although the PAC provided guidance throughout the project, the views presented in this report are those of the authors and not necessarily a consensus of the PAC members.



## Project Methods (continued)

- **Membership:** Current membership of the PFAC, including the percentage of PFAC members who are patients or family members.
- **Member support:** Mechanisms in place to support meeting participation (e.g., language and translation services, options for virtual participation, travel reimbursement).
- **Recruitment and selection:** Procedures that guide identification and selection of new PFAC members.
- **Orientation and education:** Procedures related to providing formal orientation for new PFAC members and opportunities for continuing education.
- **Serving on committees:** Patient and family member representation on specific hospital committees, teams, and task forces.
- **Reporting and evaluation:** Procedures for documenting the PFAC's work through annual evaluations and self-assessments.
- **PFAC activities:** Responsibility for initiating PFAC activities (PFAC vs. leadership and staff members), extent of feedback to PFAC about its recommendations.

The survey was distributed by the New York State Partnership for Patients (NYSPFP)<sup>7</sup> to its hospital contact list in June 2017. The list of hospital contacts was augmented with information from members of the PAC. The survey was e-mailed to patient experience staff at 170 of the approximately 190 acute care hospitals in New York State. After a three-month survey administration period that included follow up with nonrespondents, we received valid responses from 110 hospitals (64.7% of contacts, 58% of all acute care hospitals in New York State). These hospitals represented 79% of the 29 largest New York State hospitals by discharge numbers, with 62% of New York State counties represented.

### Linkage of Survey Data to Other Datasets

Following completion of data collection, the project team linked survey responses to hospital demographic data from the New York State Department of Health (NYSDOH) at the individual hospital level. Survey data was also linked to individual-level hospital quality measures.

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<sup>7</sup> The NYSPFP is a joint initiative of the Healthcare Association of New York State and the Greater New York Hospital Association. NYSPFP was created in 2011 to participate in CMS' Partnership for Patients initiative to improve the quality and safety of health care provided in hospitals across the State.



## Project Methods (continued)

including Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) and safety metrics from CMS.

### Data Analysis

Preliminary data analysis included comparing demographic data from respondent hospitals to nonrespondent hospitals and running frequencies to look at the prevalence of PFAC existence and the state of PFAC development among survey respondents.

To summarize PFAC performance among those hospitals that had at least one hospital- or unit-level PFAC, nine indices were created from the survey categories. Each index was constructed by taking the mean of the sum of the responses to each question in the category, using responses only from those respondents that answered at least 50% of the questions.<sup>8</sup>

A key goal of a PFAC is to influence a hospital's policies, strategies, and operations. Therefore, the project team used a question that asked how much the respondent felt their PFAC influenced hospital leadership, policies, and operations to assess the criterion validity of the study's ultimate performance indicator (which was constructed from a subset of the indices described above). The project team performed pairwise correlations between each index and the criterion variable and found that the orientation, committee participation, and evaluation indices were most strongly related to the criterion validity measure of influence (see Table 4 on page 55). The project team therefore defined high-performing PFACs as those scoring in the top 50% of the orientation, committee participation, and evaluation indices.

“Now, walking the halls, there is a different feeling that has been facilitated and influenced by the Family Advisory Council. It is making actionable change.” —*Staff Project Coordinator*

The final step was to explore whether PFAC status (whether or not there is a PFAC and whether the PFAC is high- or lower-performing) was related to the following CMS quality and safety metrics:

<sup>8</sup> Table 3 (see pages 53-54) shows the questions contained in each index as well as the range and average score. In all cases, a higher score on the index indicated higher functioning in that area. Table 4 on page 55 shows the inter-correlation of the indices.



## Project Methods (continued)

- **HCAHPS variables** concerning overall hospital rating, likelihood of recommending the hospital, nurse communication, doctor communication, staff responsiveness, pain management, communication about medications, discharge information, and care transitions.
- **CMS safety metrics**, including *C. difficile* infection, pressure ulcers, sepsis and septic shock, surgical site infections following colon surgery, surgical site infections following abdominal hysterectomy, post-operative pulmonary embolism or deep vein thrombosis, and 30-day hospital-wide readmission.

A bivariate analyses was first performed associating the HCAHPS and CMS safety metric variables with the PFAC performance variable. A one-way analysis of variance was used to test for statistically significant associations. The project team then performed linear regression analyses associating PFAC performance with select HCAHPS and CMS safety metric variables. These multivariable analyses controlled for potential confounding factors, including number of beds in the hospital and average charges for patients in the hospital. Based on these linear regression models, the project team computed predicted values for each dependent variable at each level of PFAC performance.

### INTERVIEWS AND SITE VISITS

#### State-Level Key Informant Interviews

In conjunction with survey data collection, key informant interviews were conducted with organizations in states that have initiatives to increase the adoption of PFACs (California, Kansas, Michigan, Minnesota, North Carolina, and South Carolina). The project team contacted organizations that had experience with and knowledge of PFAC development or that had directly supported statewide PFACs. Members of the project team conducted telephone interviews with key informants from six states, asking questions about:

- Mechanisms at the state level that facilitate the development, maintenance, and sustainability of PFACs (e.g., state mandates, health insurance plan incentives, provider education);
- Lessons learned from state-level initiatives; and
- Other resources or initiatives that have the potential to facilitate PFAC development.

Information about the experience of a seventh state, Massachusetts, was obtained through the participation of two PAC members who had been actively involved in the statewide development of PFACs there.



## Project Methods (continued)

### Follow-Up Interviews and Site Visits with Survey Respondents

Hospital respondents of the online survey were asked about their willingness to participate in follow-up interviews or site visits to further explore survey answers; 51 respondents indicated willingness for follow-up. The project team identified respondents with existing PFACs, PFACs in development, and no PFAC. One-on-one telephone interviews were conducted with five individuals who had previously completed the survey and in-person site visits with three hospitals that had high-performing PFACs, as indicated by survey responses.

The interviews and site visits were guided by semi-structured protocols. Hospitals with current PFACs were asked about PFAC accomplishments; challenges and barriers; and factors that contributed to the PFAC's ability to influence hospital leadership, strategy, and operations. Participants were also asked to provide more details about how their hospitals provide formal orientation for PFAC members, conduct annual evaluations, and involve PFAs on other hospital committees and teams (i.e., the indices denoting high-performing PFACs in the survey). Hospitals with PFACs in development were asked to describe the development process; development roles and responsibilities; and challenges and barriers. For hospitals with no PFAC, we asked respondents whether the hospital had a PFAC in the past and what barriers and challenges existed. The project team asked all participants in the follow-up interviews about additional tools and resources that would be useful in their continued work to develop and sustain effective PFACs. During the site visits, the project team also participated in other activities, including discussions with hospital and PFAC leaders and attendance at PFAC meetings.

### Qualitative Data Analysis

Detailed notes were taken during the statewide interviews, follow-up survey interviews, and site visits. The team, including project staff who were not involved in data collection, reviewed notes to identify key themes and concepts, quotes of particular interest, and recommendations. The project team held multiple meetings to discuss qualitative analysis, emerging findings, key themes, and recommendations.



## Survey Results

Respondent hospitals to the online survey were similar to New York State hospitals on key demographic criteria including patient gender, patient age, and average costs and charges (see Table 5 on page 56). Respondent hospitals did, on average, have a shorter patient length of stay than nonrespondent hospitals.

### PFAC Prevalence

Of the respondent hospitals, 59.1% reported having a current PFAC; an additional 12.4% reported having a PFAC in development. Of hospitals that reported being part of a multihospital system, 30% reported having a PFAC at the system level (see Table 6 on page 57). For hospitals with current PFACs, the average number of PFACs within a given hospital was 2.6 (SD = 1.7). Hospitals with PFACs tended to have slightly younger patient populations and were less likely to be in a rural county, but otherwise were similar to hospitals without PFACs. Hospitals with PFACs in development were more likely to be critical access hospitals and hospitals in rural counties (see Table 7 on page 57).

### PFAC Characteristics

Hospitals that reported having a PFAC were asked a series of follow-up questions to collect information about the structure, operations, membership, and characteristics of their PFACs (see Table 8 on pages 58-59).

#### *Structure*

The majority of hospitals reported that their PFACs have a charter that informs operations (81%), although a smaller percentage (64.9%) have written goals to guide their work. Although nearly all PFACs have a staff champion (93.6%) and a staff liaison responsible for overseeing the work of the PFAC (95.2%), only 23.2% of PFACs have a defined place within the hospital's organizational structure. Approximately two-thirds of PFACs in the sample (65.6%) have membership that includes more than 50% patients and family members, but only slightly more than half have a patient/family member as chair or co-chair (54.8%). Over three-quarters of hospitals with PFACs (78.3%) report providing PFACs with the opportunity to serve as e-advisors (i.e., advisors who participate virtually via e-mail and online platforms).

#### *Operations*

Currently, only half of New York State PFACs report meeting at least 10 times per year. Hospitals also report that very few PFAC meetings are guided by an agenda (3.3%), and most do not provide minutes to summarize each meeting (only 10% do so).



## Survey Results (continued)

### *Orientation*

Less than 20% of hospitals report providing a formal orientation for their PFAC members (18.3%), although slightly more report providing training for PFAs in conjunction with special placements (50%) and opportunities for continuing education (55.2%).

### *Reporting*

The majority of PFACs indicated that they conduct an annual evaluation (65%) and evaluations of member perceptions of participation (72.9%). In terms of reporting, 80.7% of PFACs provide an annual report to the board of trustees, although it is unclear what information this annual report contains about PFAC activities, as only 21.7% of PFACs document activities and only 11.3% report the outcomes of PFAC activities to the board of trustees.

### *Recruitment and representativeness*

Survey results also provided insights into PFA recruitment, with staff referral emerging as the most common recruitment method (95.2%). PFA referrals (PFAs referring other patients and family members) were also an important source of recruitment for 54.8% of hospitals. A smaller percentage reported recruiting PFAs via the hospital website (30.7%) and hospital publications (25.8%).

Although more than 70% of respondents viewed their PFACs as representative of the patient population in terms of age, gender, and health conditions, participants noted more challenges with representativeness in terms of race, language spoken, and particularly socioeconomic status.

### *PFAs on hospital committees*

In terms of having PFAs serve on other hospital committees, it was most common for PFAs to serve on patient experience committees (64.5% report having PFAs on the patient experience committee). Less than two-thirds of hospitals with PFACs reported having PFAs on their safety, facility design, health information technology, staff and physician education, or diversity/inclusion committees. And, less than 2% reported that PFAC members serve on the board of trustees.

### **PFAC Performance**

As described above, PFACs were categorized as high- and lower-performing; high-performing PFACs were those that scored in the top 50% of the orientation, committee, and evaluation indices. Of the 59 hospitals in the sample that reported having a PFAC, 29% were defined as high performing. These PFACs tended to have been in existence longer and to be from larger



## Survey Results (continued)

hospitals by number of beds (see Table 9 on page 60). Hospitals with high-performing PFACs also scored higher on most of the other constructed indices related to structure, operations, recruitment, membership, member support, and reporting (see Table 10 on page 60).

### Association with HCAHPS Scores and CMS Safety Metrics

High-performing PFACs had higher overall HCAHPS ratings (87.2%) than lower-performing PFACs (86.5%), which in turn had higher ratings than hospitals with no PFAC (84.7%). This association was demonstrated at a trend level ( $p < 0.10$ ) (see Table 11 on page 61). For patients' likelihood to recommend the hospital, the association was present at a statistically significant level (87% vs. 86.3% vs. 83.5%;  $p < 0.05$ ). For the relationship with the CMS safety metrics, high-performing PFACs had lower rates of pressure ulcers ( $p < 0.05$ ), sepsis and septic shock ( $p < 0.01$ ), and 30-day hospital-wide readmissions ( $p < 0.01$ ) than lower-performing PFACs.

When controlled for bed size and total charges (see Table 12 on page 61), the associations between HCAHPS scores and PFAC status remained statistically significant. Compared with hospitals with no PFAC, hospitals with a lower-performing PFAC were likely to see a 2-point difference in their HCAHPS overall hospital ratings ( $p < 0.10$ ) and a 3-point difference in the percentage of patients who would recommend the hospital ( $p < 0.05$ ). Hospitals with a high-performing PFAC were likely to see a 3.5-point difference in mean hospital rating compared with hospitals with no PFAC ( $p < 0.05$ ) and a 4-point difference in percent of patients who would recommend the hospital ( $p < 0.05$ ).

With the CMS safety metrics, hospitals with a PFAC had significantly better performance on 30-day readmissions, pressure ulcers, and sepsis as compared with those hospitals with no PFAC (see Table 12 on page 61). In most cases, the presence of the PFAC was the defining factor, regardless of whether the PFAC was high- or lower-performing. For example, hospitals with a lower-performing PFAC had a predicted incidence of pressure ulcers of 0.0003 compared with 0.0004 in hospitals with no PFAC ( $p < 0.05$ ), but there was no difference observed between hospitals with high- and lower-performing PFACs (see Table 13 on page 62). Similar trends were seen for sepsis and septic shock, with both high- and lower-performing PFACs seeing lower incidences compared with hospitals with no PFAC. For 30-day readmissions, there was a demonstrated difference between high- and lower-performing PFACs—hospitals with no PFAC had a predicted incidence of 0.20, whereas hospitals with a lower-performing PFAC had a predicted incidence of 0.127 ( $p < 0.01$ ) and hospitals with a high-performing PFAC had a predicted incidence of 0.131 ( $p < 0.05$ ).



# Interview and Site Visit Findings

## STATEWIDE INTERVIEW FINDINGS

Based on knowledge of the field, individuals for key informant interviews were selected from states where PFAC development has received statewide attention or support (California, Kansas, Michigan, Minnesota, North Carolina, and South Carolina). Information about the experience of a seventh state, Massachusetts, was obtained through the participation of two PAC members who had been actively involved in the statewide development of PFACs there.

During the interviews, key informants identified state- or regional-level entities that supported the development and initiation of PFACs, and also described the roles of these entities and types of support provided. In addition, key informants identified opportunities for providing additional resources and support to facilitate PFAC creation and the implementation of best practices.

### Support for PFAC Development and Initiation

Key informants noted certain factors as important in providing impetus for the development of hospital-based PFACs:

- **Federal government quality initiatives.** Some informants noted the importance of federal government quality initiatives that, while not mandating the creation of PFACs, incorporate work with PFAs into program goals and objectives. For example, CMS' Partnership for Patients initiative includes five specific metrics that assess PFE at the hospital level. One of these metrics asks whether hospitals have a PFAC or include PFAs on hospital quality or safety committees.
- **Reimbursement or incentives for PFACs.** Informants also noted the impact of programs that provide reimbursement or create incentives for the creation of PFACs. For example, in California, the California Medical Assistance Program requires each health plan to establish a family advisory council. In Kansas, Michigan, and South Carolina, Blue Cross/Blue Shield reimburses hospitals based on the presence of a PFAC.
- **State-level mandates.** Since 2008, Massachusetts has mandated that all hospitals in the state have PFACs. The regulations further specify requirements for PFACs that include best practices such as: at least 50% of the PFAC members must be current or former patients or family representatives; hospitals must develop written descriptions of the PFAC's purpose, goals, membership eligibility, and member roles and responsibilities; and hospitals must write an annual report on the work of the PFAC. Although there were challenges, including the lack of funding earmarked for implementation, key informants still noted the influence of the legislation in spurring the creation of PFACs across the state.



## Interview and Site Visit Findings (continued)

At the same time, key informants noted that the impetus for PFAC creation often does not come with accompanying support for implementation. The organizations and entities noted as providing ongoing support related to the initiation and sustainability of PFACs include: hospital associations; state-level task forces; patient safety organizations (e.g., California, Michigan, North Carolina); state or regional quality associations; departments of health; Hospital Improvement Innovation Networks (HIINs) and Quality Innovation Network-Quality Improvement Organizations; hospital-based foundations (e.g., the Lucille Packard Foundation for Children's Health); and statewide consumer health advocacy organizations. In particular, hospital associations at the state and regional level were identified as having an important influence. In addition to providing education, training, and support, key informants noted that hospital associations can help advance work by conducting surveys and assessments to understand the prevalence and functioning of PFACs in the state, as well as conducting research about best practices.

A primary way in which the organizations listed above provide support is through learning events that focus on patient- and family-centered care (PFCC) practices, such as annual meetings, webinars, workshops, in-person site visits, and trainings. Key informants also noted the importance of integrating PFE and PFCC into learning events that focus on hospital quality and safety, creating an explicit connection between PFCC and other outcomes. Further, key informants noted that some organizations create attendance requirements for learning events that stipulate hospital staff must attend with PFAs.

Another way in which organizations facilitate ongoing work with PFAs is through outreach to and support of hospital leadership, quality managers, and other quality and safety staff. This outreach can occur via direct communication or programs such as leadership retreats.

Finally, key informants noted that state-level organizations, such as hospital associations, play an important role in spotlighting work related to PFCC. For example, key informants mentioned the visibility created through providing volunteer awards for PFAs or recognition awards for hospitals that are PFCC exemplars. In addition, social media campaigns at the state level can raise awareness of PFACs, highlight the importance of working with PFAs, and recognize specific hospitals for their efforts.

### **Opportunities for Additional Support**

Key informants identified additional needs and opportunities for support at the state or regional level, related both to development of new PFACs and sustainability of existing ones. Importantly, key informants noted the need for and benefit of tailored guidance that



## Interview and Site Visit Findings (continued)

addresses different models for PFAC development. As one key informant noted, “We need to accommodate different levels and needs of hospitals as they develop PFACs; not everyone is ready for the highest level.”

Key informants reported that the following state-level support would be helpful to hospitals moving forward:

- **Opportunities to share learnings.** Key informants noted the relative lack of opportunities for networking at the state or regional level, observing that the ability to create relationships is currently dependent upon individual connections. Key informants stated that guided sessions to share learnings, online communities to exchange resources, and regional networking would enhance opportunities to share best practices.
- **Mentorships.** Related to creating opportunities to share learnings, key informants noted the potential benefits of pairing mentor hospitals with those that are less experienced, providing peer support on an ongoing basis.
- **Individualized coaching.** As one key informant said, “Developing a PFAC is not intuitive and can be overwhelming, especially for critical access hospitals.” Individualized coaching provides an opportunity to offer tailored guidance and create action plans that address the different needs and journeys of hospitals in developing PFACs. One key informant described this type of individualized coaching, which can occur via coaching calls or on-site visits, as pivotal, particularly for struggling hospitals.
- **Toolkits and additional training resources.** Key informants mentioned the need for generic tools and resources related to PFAC development, including how to conduct meetings, recruit members, and provide orientation.

When asked about best practices for PFACs, key informants mentioned visible leadership support, dedicating resources as part of the operations budget to support the PFAC, and reporting growth and impact of work with PFAs. Key informants also encouraged expanded thinking about ways in which to work with PFAs (i.e., beyond a PFAC) and spoke about the emphasis on tying PFAC development primarily to HCAHPS scores as limiting.

### **SURVEY FOLLOW-UP INTERVIEW AND SITE VISIT FINDINGS**

The follow-up interviews and site visits conducted with survey respondents identified facilitators for initiating and maintaining an effective PFAC and PFAC best practices. Interview participants also identified resources that would be helpful in supporting and advancing work with PFACs.



## Interview and Site Visit Findings (continued)

### Facilitators

Participants spoke about both barriers to and facilitators for initiating and sustaining an effective PFAC. Because the facilitators described by participants were specifically identified as ways to move past the stated barriers, the interview and site visit findings have been framed in terms of strengths. In doing so, the project team finds that the presence of these aspects is important, and their absence can be damaging. Notably, although some participants mentioned staff burden, workload, and financial resources as barriers to the development of a PFAC, these were not strong or predominant themes in the interviews and site visits.

#### *Facilitator 1: Leadership buy-in*

Interview participants referred to the concept of leadership buy-in in varying ways, using terms such as "executive-level sponsorship," "leadership commitment and involvement," and "leadership investment." Participants noted that buy-in at the senior leadership level was important not only for initiating but also for sustaining work with PFAs. In describing leadership buy-in, some participants noted that leaders at their hospitals were invested in working with PFAs from the beginning. Others described situations in which hospital leaders had reservations about working with PFAs, or felt that the organization was already patient- and family-centered. In these cases, there was a process of obtaining buy-in that included presentations to and conversations with executive-level leaders. Important components of these conversations included highlighting existing bright spots within the organizations that served as exemplars of PFCC, and involving patients and families by having them share their stories with hospital leaders. Leadership participation in PFAC meetings was also noted as important in sustaining engagement and buy-in over time.

"We are so fortunate to have the perspective of patient and family advisors. Staff and clinicians can get so lost in the words we use and the intensity of the work." —Hospital CMO

#### *Facilitator 2: Staff and clinician buy-in and participation*

Staff and clinician buy-in was also reported to be important to PFAC initiation, effectiveness, and sustainability. Participants noted that obtaining this buy-in requires directly addressing attitudes and perspectives that serve as barriers—for example, addressing concerns that PFAs will raise only complaints. Other barriers include an "us-versus-them" mentality that frames the relationship with patients and families in terms of conflict rather than partnership.



## Interview and Site Visit Findings (continued)

Participants noted several factors as being important in moving past these barriers, including training and education to increase staff awareness of PFAs/PFACs and the benefit of their work; providing staff members with the opportunity to interact with PFAs and participate in PFAC meetings; and creating opportunities for PFAs, clinicians, and staff members to share their stories with each other. The sharing of stories was described as particularly helpful in breaking down barriers on both sides, with one patient advisor noting, "I realized that the [medical] residents are just like us. They are people...they were listening."

"At first the PFAC overwhelmed me, but I now realize that the PFAC helps me do my job better." —*Staff member of a PFAC*

### ***Facilitator 3: Connection of PFAC work to broader organizational priorities and growth***

Participants spoke about the importance of grounding patient and family advisors' work in relation to organizational-level goals and strategies. In this way, the PFAC supports broader quality and safety initiatives and advances progress toward shared goals. In contrast, having a narrow vision of the type of work that PFAs can do or the types of projects in which they can be involved becomes a barrier to sustaining an effective PFAC. Several participants described this narrowed vision in terms of concentrating work with PFAs solely on patient experiences of care, leading to missed opportunities for partnership. Participants also noted the importance of a growth mentality, working over time to expand roles for PFAs; creating PFACs for specific populations (e.g., youth advisory councils); embedding the PFAC into the hospital's organizational structure; hiring patient and family leaders, including PFAs on other hospital committees and workgroups; and expanding work with PFAs into the ambulatory care setting.

"Before you start, make sure a PFAC fits into your hospital's culture and lay the groundwork." —*Hospital Association Staff*

### ***Facilitator 4: Realistic expectations coupled with the ability to adapt and respond to challenges***

Nearly all interview participants noted challenges associated with the journey to implement and sustain work with PFAs. These challenges were often similar across hospitals, and included difficulties with recruitment, identifying meaningful work for PFAs, and sustaining energy over time. Participants described several factors that were important in weathering



## Interview and Site Visit Findings (continued)

challenges. First, participants noted the benefit of realistic expectations and a longer-term mindset. They described the partnership with PFAs and PFACs as an evolution with a timeline that spans years, as opposed to expecting overnight results. Second, participants noted the importance of flexibility and resiliency in responding to and moving past the challenges that inevitably arise.

### *Facilitator 5: Presence of a culture of PFCC and partnership*

As noted by participants, a significant facilitator of successful work with PFAs is the development or presence of an organizational culture that is rooted in a deep understanding of the principles of PFCC and the benefits of authentic involvement of patients and families. Participants noted that this involves a strong belief in partnership at all levels of the organization—from leadership to frontline staff—and across all departments. Participants described a culture of PFCC in terms of always asking “what is important to patients and families,” and asking “how would this project affect families,” and partnering with patients and families from the beginning when new projects are initiated. The importance of co-design—involving patients and families in meaningful ways from the start—was particularly highlighted. During one site visit, a family advisor emphasized this point, stating, “If I’m going to be involved, I want to be involved throughout.”

“In the past, we never would have asked, ‘How would this project impact families?’ or ‘What are families’ perspectives?’ But the culture is shifting and, today, these questions are always asked.” —*Administrative Director*

A cross-cutting theme that emerged in relation to all facilitators was the importance of storytelling. Participants noted that patients’ stories created the impetus for work with PFAs; fostered connections with clinicians and staff members; and provided inspiration and energy for sustaining the work over time. Participants also noted the importance of having clinicians and staff share their stories—connecting individuals with their dual role as both health care providers and patients/family members and helping them forge connections with PFAs.

“I am most proud of sharing my story and my perspectives about care in the ICU and then seeing the change in practice.” —*Patient Advisor*



## Interview and Site Visit Findings (continued)

### PFAC Best Practices

In discussing what it takes to sustain an effective PFAC, interview participants mentioned multiple best practices. Although not an exhaustive list, these best practices include:

- **Continued emphasis on recruitment:** Participants spoke about the importance of maintaining an active recruitment program with continuous attention to recruitment. This was noted as particularly important for ensuring diversity of PFAs that is reflective of the hospital's patient population.

### A NEW YORK STORY

A long-established PFAC that has grown significantly in recognition and impact still struggles with recruitment of new members, especially those that truly represent the hospital's patient population. And, orientation of new PFAC members is described by the staff liaison as "not formal." Currently the hospital is enhancing PFA orientation and has formalized the preparation of advisors serving on unit-based improvement teams.

- **Advisor orientation and training:** Participants noted that orientation programs for PFAs help set expectations and ground rules. Orientation is a process that begins during recruitment and continues via practices such as providing new PFAs with a more experienced PFA mentor and holding check-in meetings with new PFAs after initial PFAC meetings.
- **Start with small projects:** Participants from well-established PFACs spoke about the importance of beginning with small, manageable projects that provide opportunities for success. These early wins provide a model of partnership and serve as a foundation for future work.

### A NEW YORK STORY

After attending a seminar about PFCC, a team from a 25-bed critical access hospital was inspired. One month later, the PFCC action committee at the hospital recruited one patient to tell his story to leadership. Within another three months, the committee brought on two other advisors and held their first PFAC meeting. A discussion about hospital signage led to an immediate impromptu tour—ultimately leading to suggestions for changes.



## Interview and Site Visit Findings (continued)

- **Follow-through and feedback:** Following through on feedback and input from PFAs was described as important in sustaining their involvement and engagement over time. As one PFA stated, “I am a mom who has no time for ‘talk-talk.’ I want to see real changes.” Participants also noted that communicating with advisors about changes to policies, programs, and practices highlights the impact of their efforts, and signals that the organization is committed to translating PFA input into action.

“We are not a rubber stamp. I see the changes we are making.”

—Patient and Family Advisor

### Resources Needed

During the interviews and site visits, participants were asked what would be helpful in supporting continued progress toward meaningful partnerships with PFAs. The following items were cited:

- **Federal and State-level prioritization of the work.** Participants cited the influence that federal and State initiatives can have, particularly noting CMS’ Partnership for Patients initiative and the Healthcare Association of New York State’s emphasis on PFACs as a 2017 priority.
- **Educational and training events.** Multiple participants spoke about the positive impact of seminars and trainings that showcase success stories and provide opportunities for experiential learning. These types of trainings were seen as not only practical but also inspirational. Participants noted that it was helpful to have opportunities that incorporate a variety of learning formats, including conferences, seminars, and workshops.
- **Resources and tools.** Participants described the need for a range and variety of resources to support development and maintenance of PFACs. Specifically, participants identified a need for additional information and tools targeted toward executive leaders, helping them understand the importance and benefit of PFACs. Strategies and resources related to recruitment of PFAs were also a need mentioned by several participants.
- **Coaching and support.** Multiple interview participants spoke of the benefit of individualized technical assistance and coaching. The desire for this type of guidance was strong, with some interviews evolving into informal coaching sessions. The perceived benefit of coaching appears to be the ability to receive information and support customized to specific challenges or organizational circumstances.



## Interview and Site Visit Findings (continued)

“For PFACs to develop, coaching and support must be provided to every hospital in our system.” —*Director of Social Services*

- **Peer-to-peer learning.** Multiple participants mentioned the benefit of connecting with other hospitals via site visits and other mechanisms. There was a strong desire to learn from other hospitals, particularly those that are similar in terms of patient demographics, hospital size, location, resources, and challenges. Participants also expressed a need for better cross-fertilization of experiences and lessons learned between hospitals and among and across systems, noting that most hospitals are currently very insular.
- **Metrics and measurement.** Although not mentioned as frequently, some participants noted the need to better understand what to measure so as to demonstrate progress and the impact of work with PFAs, including how to tie the work to quality and safety outcomes.



# Key Results

## PREVALENCE OF HOSPITAL-BASED PFACS

Results from this project indicate both strengths and opportunities for improvement related to the prevalence of PFACs in New York State and the adoption and implementation of PFAC best practices.

Fifty-nine percent of New York State hospitals in the sample reported having an existing PFAC. Given the relative lack of state-level data about the prevalence of PFACs, it is difficult to create a comparison about the prevalence of PFACs in other states. However, to put the information in context, data from NYSPFP's HIIN initiative indicate that 54% of the 176 participating hospitals report having a PFAC or at least one PFA who serves on a hospital committee.<sup>9</sup> A 2015 study involving 1,457 U.S. hospitals found that 38.4% reported having hospital-wide or unit-based PFACs.<sup>10</sup> Therefore, although surveys were not collected from all hospitals in New York State, the information about the prevalence of PFACs in the State is encouraging. Moreover, the survey results suggest continued momentum, with 12% of hospitals in the sample reporting that they have a PFAC in development.

The survey results also may highlight the effects of initiatives within New York State to promote and support PFACs. The 12% of hospitals that reported having PFACs in development were more likely to be critical access hospitals and hospitals in rural counties. The progress in this group of hospitals may reflect the results of work by NYSPFP, which provided training specifically for rural and critical access hospitals in fall 2017 to help them establish and sustain meaningful partnerships with PFAs. In May 2018, the HIIN held two statewide, all-day educational programs on the development of PFACs, with follow-up coaching support.

In recognizing forward momentum, however, it is also important to note that nearly 30% of hospitals reported having neither a PFAC nor plans to develop one. There is relatively little information about these hospitals, as an in-depth exploration of the experiences of hospitals with no PFACs was outside the scope of this project. However, this may be an indication of barriers related to lack of knowledge about the purpose and benefits of working with PFACs; lack of leadership support for PFACs; or concerns about potential implementation challenges. Additional targeted studies may be needed with these hospitals, as well as with

<sup>9</sup> HIIN PFE Metric Data. March 22, 2018. HIINgagement newsletter.

<sup>10</sup> Herrin J., Harris K.G., Kenward K., et al. Patient and family engagement: a survey of US hospital practices. *BMJ Quality & Safety* 2016;25:182–189.



## Key Results (continued)

nonrespondent hospitals, to better understand—and subsequently address—challenges to PFAC implementation.

### PFAC BEST PRACTICES

In providing training and technical assistance to health care organizations that are establishing and furthering work with PFACs, IPFCC and other organizations have advocated for the use of specific best practices. These best practices—which shaped the content of the online survey—have been informed by decades of on-the-ground implementation work with hospitals, ambulatory practices, and other health care organizations, along with knowledge gleaned from the field. This project sought to augment, verify, and further understand the relative importance and influence of these and other best practices. The results verify the importance of many existing best practices, both in relation to creating a supportive environment and culture in which a PFAC can thrive and in relation to the operation and work of a PFAC itself.

### Supportive Culture

A critical factor in organizations that are successful in establishing and sustaining PFACs is a culture that is supportive and committed to authentic and meaningful partnerships. Facilitators of high-performing PFACs include a strong emphasis on leadership buy-in and support. Senior leaders can create both the impetus and sustained momentum for partnerships with PFACs. They have a particularly important role to play in linking PFAC work to broader organizational priorities and initiatives, ensuring that the PFAC work is not siloed or relegated only to improving patient satisfaction. Leaders can also help foster resiliency during periods of challenge and provide vision related to the evolution of the PFAC over time. As noted, most PFACs struggle at some point with aspects of their work or functioning. The ability to work through, adapt, and respond to these challenges is an indicator of likely success. Finally, leaders can also help develop plans to ensure staff member and clinician buy-in, which should be supported through consistent, ongoing education.

## A NEW YORK STORY

At a 250-bed hospital, the CEO leads the charge about the importance of the PFAC's role. He consistently asks other leaders and clinicians if they have gone to the PFAC with new initiatives or programs. He receives and reviews all the minutes from PFAC meetings. At the board level, too, PFAC input is sought and used. The board has met with the PFAC to elicit members' help with the redesign of the hospital. As the board was discussing community health issues, it directly asked the PFAC, "What do you think is the hospital's role in community health?"



## Key Results (continued)

### Operations and Work

The study findings reinforce what has been learned over time about other practices employed by exemplary PFACs—that is, PFACs that embody authentic partnerships with patients and families, perform meaningful work, and sustain partnerships over time.

Table 1 lists these PFAC best practices.

TABLE 1. Exemplary PFACs—Best Practices

#### PFAC structure and membership

- The PFAC has an executive sponsor and staff liaison.
- There is a defined relationship between the PFAC and the hospital/health system leadership and board of directors.
- More than 50% of PFAC members are PFAs; PFAs are representative of the patient populations served.

#### Recruitment

- Recruitment is an ongoing program rather than a one-time event.
- Recruitment strategies are designed to ensure that the PFAs reflect the diversity of communities served.
- Clinicians and staff members help identify potential PFAs; other contacts and resources available through the hospital are used (e.g., support groups, relationships with community organizations).

#### Onboarding and orientation

- Onboarding and orientation are provided to all PFAC members, covering the key elements of the role of a PFA and helping orient PFAs to hospital quality and safety work.

#### PFAC operations

- The PFAC meets regularly, approximately 10 times per year.
- There is an agenda for each PFAC meeting, ideally developed by a PFA chair or co-chair, or by the PFAC.
- Language/translation services, childcare, parking/transportation, and even stipends are provided to encourage participation, especially among disadvantaged populations.

#### Opportunities offered to PFAs

- The hospital offers a variety of ways to serve as PFAs, including virtual opportunities and full membership on key committees, quality improvement and safety teams, and governing boards.

#### Feedback, evaluation, and reporting

- PFAs receive feedback about the impact of their work.
- There is an annual PFAC evaluation that measures the outcomes and impact of PFAC activities and initiatives.
- An annual report is prepared to summarize PFAC accomplishments and future plans and shared broadly with the health system and the community.

### Variability in PFAC Best Practices

In addition to verifying the importance of best practices, the results also showed the variation in hospital-based PFACs within New York State in terms of those practices related to composition, structure, resources, management, and functioning.



## Key Results (continued)

“My vision for the PFAC is that we reach a point where PFA members drive the council—plan the agenda, run the meetings, and decide the things we need to do.” —*PFAC Staff Liaison*

Results from the online survey, interviews, and site visits suggest variability in terms of PFAC performance. Frequencies varied widely for items in the nine categories of best practice on the survey (from 98.3% to 1.8%). Categories in which PFACs were performing well—and those in which improvement is needed—are shown below.

### **Hospitals are performing well: best practices used by more than 75% of the hospitals**

- PFAC has a charter;
- PFAC has a staff champion;
- PFAC has a staff liaison;
- PFAC provides annual report to the board of trustees;
- Feedback about PFAC activities is provided;
- Outcomes of PFAC activities are reported to hospital leadership;
- Parking is provided; and
- There are usually at least two PFAs represented on each committee with a PFA.

### **Hospitals need improvement: best practices used by less than 25% of hospitals**

- PFAC has a defined place on the hospital's organizational chart;
- PFAC meetings have an agenda to guide meetings, along with meeting minutes distributed after;
- Formal orientation is provided;
- PFAC documents its activities;



## Key Results (continued)

- Outcomes of PFAC activities reported to board of trustees, community;
- Transportation provided; and
- Childcare provided.

### Opportunities for Adoption and Implementation of Best Practices

In addition, the study results also show that, even among well-established PFACs, there are opportunities for further adoption and implementation of best practices. Overall, the results suggest several areas of opportunity for PFACs in New York State.

The first area of opportunity is related to **embedding PFACs within hospitals' organizational structure** and ensuring a clear channel of communication with hospital leadership. In the study sample, less than 25% of hospitals reported that their PFACs have a defined place on the hospital's organizational chart. Although the majority of hospitals (79.0%) indicated that they report outcomes of PFAC activities to hospital leadership, it is unclear how this is accomplished, as only 21.7% reported documenting their PFAC's activities.

The second area of opportunity relates to **PFAC management and functioning**. Only 3.3% of hospitals with PFACs reported having agendas for their PFAC meetings, and only 10% indicated that they develop meeting notes to document discussions, decisions, or action items. Developing agendas to facilitate productive, action-oriented meetings and recording minutes to document decisions and activities are essential for ensuring accountability and measuring progress over time.

**Recruitment of new members** was discussed as a concern in many of our interviews and represented almost 25% of the responses from hospitals with lower-performing PFACs on an open-ended survey question asking about challenges. Survey respondents reported that most referrals come from either hospital staff (95.2%) or current PFAs (54.8%). Hospital websites (30.7%) and publications (25.8%) were also mentioned as sources for new member recruitment; social media was cited by only 6.5% of survey respondents. Information gathered during respondent interviews suggests that there is little evidence or shared experience on what works (i.e., what strategies are effective).

**Implementing practices that support the participation of diverse individuals** is a fourth area of opportunity. For example, most hospitals do not provide support for transportation



## Key Results (continued)

to PFAC meetings (beyond providing parking), nor do they provide childcare, which can be particularly helpful to lower-income, working individuals. Only a third of hospitals provide the option for virtual participation in PFAC meetings. Although the majority of hospitals in the survey reported that their PFAC membership was representative of the patient population in terms of age, gender, and health conditions, 40.3% indicated that their hospital PFACs were not diverse with regard to socioeconomic status. In the effort to recruit advisors that reflect hospitals' patient populations, it may be prudent to look more closely at accommodations that support the participation of diverse individuals.

The fifth area of opportunity relates to **PFA ownership of the PFAC**. Although the majority (65.6%) of hospitals with PFACs report that at least 50% of PFAC members are patients or family members, over a third have PFACs where the predominant PFAC membership is from hospital leaders, clinicians, and staff. This can present challenges with regard to the dynamics and balance of power. In addition, many hospitals appear to rely on staff members to guide and lead the PFAC. Only 28.1% of respondents indicate that at least half of the PFAC activities were initiated by the PFAC itself.

Another area of opportunity relates to **preparing and orienting patients and families** to serve in the PFA role. Less than 20% of hospitals in the study sample reported providing any type of formal orientation. As a best practice, providing PFAs with orientation and training helps them understand the context in which their work is occurring; the individuals with whom they will be interacting; how the work of the PFAC supports PFCC and relates to broader quality and safety improvement initiatives; and the logistics, responsibilities, and expectations associated with their role as a PFA.

Finally, there are opportunities to increase **integration of PFAs as members of hospital committees**, outside of the PFAC. Although nearly two-thirds of hospitals with PFACs reported that PFAs served on the patient experience committee, less than 25% reported that PFAs served on committees related to staff and physician education; student and trainee education; health information technology; research; and diversity and inclusion. With regard to critical committees that affect patient outcomes (e.g., quality and safety, patient and family education), less than 40% of hospitals report including PFAs.

### Building on Strengths

In looking at these areas of opportunity, there are also strengths upon which to build. PFACs in New York State hospitals seem to benefit from significant support from staff champions



## Key Results (continued)

(93.6%) and a staff liaison (95.2%), both key roles in organizing, promoting, and building support for a PFAC within a hospital or hospital system. In addition, many hospitals have a strong foundation from which to expand reporting and evaluation activities. Nearly all hospitals (98.3%) provide feedback to PFACs about their recommendations, 79.0% report the outcomes of PFAC activities to hospital leadership, and 80.7% provide an annual report to the hospital board of trustees. These practices can set the stage for expansion of best practices that are less frequently implemented in New York State hospitals, such as conducting annual evaluations, reporting on PFAC outcomes, and communicating with hospital staff and the community about the work of the PFAC.

### RELATIONSHIP BETWEEN PFAC CHARACTERISTICS AND OUTCOMES

The survey results also enabled the project team to assess the extent to which differences in hospital-based PFAC characteristics, and subsequent performance, are related to selected outcomes, including safety and patient experience of care. For purposes of this study, the outcome of PFAC performance was defined in terms of influence. Analysis of the survey results indicated that those PFACs that provide orientation and training, integrate PFAs into other committees, and evaluate their efforts have more influence on their hospital leadership, strategies, and operations. Therefore, these three indices defined high-performing PFACs.

Because a key function of a PFAC is to partner with an organization to improve quality, safety, and experiences of care, the relationship between PFAC status—whether the PFAC was high performing or not—and performance on CMS quality and safety metrics was also examined. The findings showed that hospitals with high-performing PFACs had the highest HCAHPS scores for hospitals included in the study, particularly with regard to the HCAHPS' "likelihood of recommending" item. However, results also showed that even hospitals with lower-performing PFACs had higher HCAHPS scores than hospitals with no PFACs. These relationships remained statistically significant after controlling for potentially confounding factors such as hospital bed size and charges. With regard to performance on the CMS safety metrics related to pressure ulcers, sepsis, and 30-day readmission, the trend was similar—however, the most significant difference was between hospitals that had a PFAC and those that did not. Hospitals with a PFAC, regardless of whether it was high- or lower-performing, tended to perform better than hospitals without a PFAC.

Although the project team did not specifically look at HCAHPS measures and CMS safety metrics for the hospitals participating in the survey follow-up and site visit interviews, among



## Key Results (continued)

those hospitals with more established, high-performing PFACs, hospital leadership and other interview participants provided multiple examples of the PFAC's work on quality and safety initiatives that could contribute to improved safety and patient experience of care. For example, one hospital interviewed reported that safety and quality discussions must be included on the agenda for every council meeting.

Although not definitive, the survey findings suggest a relationship between having a PFAC and better performance on CMS quality and safety metrics. Future research is needed to determine whether there are potential causal pathways between the presence of a PFAC, the quality of the PFAC, and improved hospital performance.

### THE EVOLUTIONARY NATURE OF PFAC DEVELOPMENT

Another important finding that emerged from the survey and interviews is that PFACs develop over time, with progress marked by small—but significant—milestones and continued attention paid to relationship- and trust-building. PFACs may experience challenges that slow progress. They may initiate new activities that ultimately are not successful. They may generate an idea for a project that is not approved by the hospital for implementation. PFACs also sometimes experience plateaus in their development when they are not involved in meaningful work. One participant in the state-level key informant interviews referred to this as the continuum of PFAC evolution/development. The survey results showing that hospitals with longer-established PFACs were more likely to be high performers also suggest the importance of time and perseverance.

“Be patient about developing a council. Hospitals are complex. It takes time for PFAs to be comfortable—to ask for more information.”

—Hospital CEO

## A NEW YORK STORY

Three years ago, a 450-bed regional medical center decided to start a PFAC—and experienced a setback. Drawing from patient surveys and complaints/grievances, 100 invitations were sent to former patients asking them to participate; only two responses were received. With support from leadership, members of the patient advocacy staff are ready to try again. This time, they plan to elicit recommendations for PFAs from staff members and clinicians and also seek help from the volunteer office. Now they realize that a single approach is not enough and they need to keep trying multiple strategies over time.



## Key Results (continued)

Results from the survey also suggest that there may be foundational elements that set the stage for continued PFAC work and progress. The survey asked about PFAC best practices related to structure, orientation, operations, membership, member support, recruitment, evaluation, reporting, and PFA membership on committees. The survey results showed that hospitals with high-performing PFACs—defined as those scoring highest on the survey indices of PFA orientation, PFAs on committees, and PFAC evaluation—also scored highest on other indices related to structure, operations, membership, and member support. Although not sufficient on their own in affecting the PFAC’s influence on hospital leadership and practices, these other indices may represent critical elements for a high-performing PFAC. These findings suggest that an important step in reaching high-performing status involves undertaking the foundational steps of establishing an effective PFAC structure (bylaws, charter, written goals, presence of an executive champion); putting in place mechanisms that facilitate operations (meeting agenda and minutes); building membership with representation from patients, families, hospital staff, and clinicians; and providing member support (childcare, transportation, language services, opportunities for virtual participation).

### Limitations

The study of prevalence and functioning of PFACs in New York State has limitations associated with survey research, including reliance upon self-reported measures. For example, hospital respondents reported their own perceptions of the influence of the PFAC on hospital leadership, policies, and operations; this could have introduced systematic bias into the survey results. Additionally, although the sample was highly representative of hospitals in New York State, the project team was unable to obtain data from the complete population of acute care hospitals within the State. Finally, respondents from the individual hospitals may have varied in terms of the degree to which they had in-depth knowledge and experience with their PFACs.

The follow-up interviews and site visits with survey respondents represent a self-selected group because they were chosen based on respondents’ willingness to participate. A relatively small number of key informant and respondent interviews and site visits was conducted, but, nonetheless, similar themes emerged across this small group.



# Recommendations

## STRENGTHENING THE INVOLVEMENT OF PFAS IN HOSPITALS IN NEW YORK STATE

This report's recommendations highlight the need to increase awareness about the impact of involvement of PFAs within hospitals and health systems and about the elements that are integral to high-performing PFACs. Additionally, the recommendations offer suggested strategies for providing support, at many levels, to New York State hospitals so that PFAC development is grounded in best practices and can occur more effectively and efficiently.

"Leadership wants families at every table. They realize that seeing it for real opens hearts and minds." —*Family Advisory Council Chair*

The five recommendations are:

- 1 Build partnerships with patients and families into State and regional quality and safety initiatives.
- 2 Create opportunities for shared learning and mentorship around PFAC work.
- 3 Develop guidance to help hospitals access existing PFAC training resources in ways that address the need for tailored information.
- 4 Conduct additional research about the evolution and impact of PFACs and expand work to other states and settings.
- 5 Disseminate PFAC study results to share learnings within and outside of New York State.

### Build Partnerships with Patients and Families into State and Regional Quality and Safety Initiatives

Findings from the state-level key informant interviews suggest the importance of regional and New York State-level initiatives in providing the impetus for work with PFAs. In addition, these initiatives and programs can model best practices for working with PFAs by ensuring that patients and families are partners at this level of policy and programmatic decision-making. The experience of other states offers both guidance and models for this work. For example, in Massachusetts, where there was a statewide mandate for hospitals to establish PFACs, the nonprofit organization Health Care For All assumed a leadership role in supporting hospitals in the development and implementation of work with PFAs. In doing so, Health Care For All established a statewide PFAC comprising PFAC staff and PFAs from hospitals across the state to help guide the work.



## Recommendations (continued)

Potential opportunities related to this recommendation include:

- **Identify New York State programs and initiatives that would benefit from PFA involvement and determine how partnerships with patients and families could be built into the work.** This includes State and community efforts related to tackling specific public health issues (e.g., the groundbreaking plan to end the AIDS epidemic in New York State and efforts to address the opioid crisis); population and community health; the implementation and use of health information technology; and health care measurement and outcomes.
- **Ensure that partnerships with patients and families are a component of State and regional demonstration projects.** As CMS continues to support the development and testing of innovative health care payment and service delivery models, there are opportunities for New York State to include PFAs in the planning and implementation of these projects (for example, through the establishment of PFACs for specific initiatives). This ensures partnership with PFAs from the beginning, integrating their perspectives in decision-making that will affect health care and services for New York State consumers.
  - New York State's Delivery System Reform Incentive Payment (DSRIP) program will implement the Medicaid Redesign Team waiver to reduce unnecessary hospital use. Clients and families using Medicaid services could serve on teams, and a PFAC could be established to offer guidance for the work. Expectations for partnering with PFAs and PFACs could be included in DSRIP toolkits and training.<sup>11</sup>
  - New York is one of eight states selected for participation in the Section 223 demonstration, also known as the Certified Community Behavioral Health Clinics (CCBHC) demonstration or the Excellence in Mental Health Act demonstration. Opportunities here include building on the existing partnerships with PFACs for CCBHCs and sharing information about these partnerships with other statewide demonstration projects.
  - NYSDOH's State Health Innovation Plan (SHIP) and its State Innovation Model initiative present opportunities to partner authentically with PFACs and PFAs. The perspectives, insights, and experiences of patients and families, as well as current PFACs and PFAs, could inform each of the five SHIP pillars: (1) improve access to all New Yorkers, without disparity; (2) address patient needs seamlessly; (3) make the cost and quality of care transparent to empower decision-making; (4) pay for health care value, not volume;

<sup>11</sup> For further information, see "Individual and Family Engagement in the Medicaid Population: Emerging Best Practices and Recommendations" (2014), [www.ipfcc.org/bestpractices/medicaid-engagement.html](http://www.ipfcc.org/bestpractices/medicaid-engagement.html).



## Recommendations (continued)

and (5) promote population health. The experience of CareOregon,<sup>12</sup> the state Medicaid health plan, with creating the Member Advisory Council (later renamed Community Advisory Council) may offer effective strategies for NYSDOH. These client and family advisors have also been effective in influencing legislation and in creating health homes, the medical home concept in Oregon.

- In future State legislation for health care improvement and innovation (e.g., legislation to address issues related to the opioid epidemic) and applications for federal demonstration projects, include authentic partnerships with patients and families at the care level and in all phases of the transformation work.
- Consider creating a PFAC for State workers' health insurance. Include these PFAs in a statewide summit (as described below).
- **Encourage other key agencies or other stakeholders in the State to model and create incentives for partnerships with PFAs** by involving PFAs, PFACs, PFAC facilitators, and health care system staff in statewide policy meetings/conferences, webinars, or other events—this includes involving them as members of the planning committee and as presenters and participants. Encourage public and private insurers to develop their own PFACs and to create reimbursement incentives for the implementation of PFACs at the hospital level.
- **Develop training and education programs to identify and prepare experienced PFAs for participation in State and regional initiatives.** To participate effectively at the State or regional level, PFAs will need additional training and preparation to help them understand terminology, policy issues, and the stakeholders involved, as well as how decisions made at the policy level affect access, cost, quality, and care delivery. Currently, few programs exist to prepare PFAs for this level of partnership.
- **Review emerging evidence about the impact of PFE on the quality, safety, and experience of care,** as well as explore specific opportunities and mechanisms for strengthening that engagement in State and regional efforts. This could be done through a statewide health care leadership meeting, or by convening a summit of key stakeholders (outlined below).

One potential opportunity to support partnerships with PFAs at this level is to convene a summit of key stakeholders in New York State to review emerging evidence about the impact of PFE on the quality, safety, and experience of care, as well as to explore specific

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<sup>12</sup> See CareOregon at [www.careoregon.org](http://www.careoregon.org).



## Recommendations (continued)

opportunities and mechanisms for strengthening that engagement. The convening of a summit also presents the opportunity to jumpstart the identification of potential PFAs to serve in meaningful collaborative endeavors at State and regional levels, as well as to gather the insights and perspectives of current PFAs and PFACs. PFAs could be identified by inviting individuals who currently serve as members of hospital-based or ambulatory-based PFACs, as well as by reaching out to PFAs in HIV/AIDS and mental health and recovery programs and PFAs working with health systems on the launch of OpenNotes. Invitations to patients and families could also be issued in community newspapers and other community communication vehicles. Experienced PFAC staff liaisons, as well as PFA leaders, could assist with planning and facilitating the summit. One of the goals of the summit should be to identify and begin the preparation of PFAs to partner at the policy level in ongoing ways.

### Create Opportunities for Shared Learning and Mentorship Around PFAC Work

Hospital staff and PFAs are eager for opportunities to learn more about the work, structure, and functioning of other PFACs. Currently, many hospitals are undertaking similar journeys as they establish and advance work with PFACs, but often are re-inventing the wheel at the individual hospital level. Hospital staff, leaders, and PFAs would all benefit from opportunities to network and learn from the experiences of their colleagues who are further along in the process of PFAC development—or who face the same challenges they do. There are several ways in which this type of shared learning and networking could be supported.

- **Collect and share voluntary annual reports from New York State hospital PFACs.** In conjunction with Massachusetts' mandate to establish PFACs at hospitals statewide, Health Care For All collected all hospitals' annual PFAC reports and posted them on the Health Care For All website.<sup>13</sup> In Massachusetts, a checklist was developed that is used by some hospitals to report their PFAC activities. Although narrative annual reports<sup>14</sup> provide more nuance and detail, a simple template could be developed to support reporting of critical elements and ease the burden for smaller or resource-challenged hospitals. Annual reports were a required component of the Massachusetts mandate; however, the collection and sharing of PFAC annual reports could be done on a voluntary basis in New York State.
- **Support PFAC-to-PFAC mentorship.** High-performing PFACs are valuable resources within New York State, and even those PFACs that are less well-established can provide helpful

<sup>13</sup> See Health Care for All, Massachusetts Patient & Advisory Councils, [www.hcfama.org/patient-and-family-advisory-councils-pfacs](http://www.hcfama.org/patient-and-family-advisory-councils-pfacs).

<sup>14</sup> See examples of exemplar PFAC annual reports at [www.ipfcc.org/bestpractices/pfa-annual-reports.html](http://www.ipfcc.org/bestpractices/pfa-annual-reports.html).



## Recommendations (continued)

information to hospitals just beginning the journey. Opportunities to leverage this base of knowledge and experience include: reaching out to high-performing PFACs from the study survey to identify potential mentor hospitals; having high-performing PFACs provide mentorship to other local PFACs, for both hospital staff and PFAs; or encouraging PFACs to attend one another's meetings. Hospital systems with multiple PFACs could bring together all PFACs periodically and/or have an overarching system-level PFAC with members from individual hospitals' PFACs. The opportunities noted above could be supported with scholarships for PFACs and hospital staff, or stipends to support the work of high-performing PFACs that agree to serve as mentors.

- **Provide train-the-trainer sessions** preparing staff members and PFAs from hospitals with high-performing PFACs to share their expertise with others, especially as related to critical challenges in the evolution/development process.
- **Conduct regional or State-level learning sessions.** Opportunities for learning about PFACs could be built into existing regional or State-level meetings (e.g., HIIN educational sessions for PFAC development), conferences, or learning events. Breakout sessions for hospital staff and PFAs on PFAC development and advancement could be conducted, with individual sessions geared toward hospitals of differing experience levels.
- **Establish virtual learning communities dedicated to New York State PFAC development and advancement.** This provides a systematic way to share successes, challenges, and project ideas. It can also create opportunities for hospitals and PFAs to connect with each other around similar challenges and work. A New York State-specific learning community could be built within an existing learning community, such as PFCC.Connect.<sup>15</sup>
- **Create mentorship programs geared toward hospital executives and board trustees.** A critical contributor to the establishment and sustainability of effective PFACs is having visible, engaged leadership. An education or mentorship program for hospital leaders could provide targeted learning about the benefits of PFACs, the specific ways in which leaders support PFAC development, and how to partner with patients and families to achieve strategic and business goals. This type of program would also provide opportunities for hospital leaders to learn more about the work being conducted at other hospitals. This type of mentorship program could be State-specific, while also drawing in mentors at the senior leadership level that have helped support the creation of PFACs at hospitals across the nation.

<sup>15</sup> See Institute for Patient- and Family-Centered Care's online learning community, <https://pfcc.connect.ipfcc.org/home>.



## Recommendations (continued)

- **Provide incentives to support hospitals in documenting and publishing the results and impact of their PFAC work.** There is still a general lack of data about the impact of work with PFAs, particularly on hospital quality and safety more broadly. Even when hospitals collect this data, they often lack resources to support publication of results in the peer-reviewed literature. Establishing a stipend or small publication award could create incentives to more broadly share the results and impact of PFAC work.

### **Develop Guidance to Help Hospitals Access Existing PFAC Training Resources in Ways that Address the Need for Tailored Information**

A consistent theme that emerged from the study findings was the need for support and tailored guidance related to the development and progression of work with PFACs. As noted above, nearly all hospitals experience challenges on the road to developing an effective, sustainable PFAC. Although mentorship and shared learning programs can provide valuable support in moving past these challenges, study participants also noted the benefit of more tailored and individualized technical assistance to help address a hospital's specific circumstances and challenges. Not all hospitals have the resources for this type of technical assistance; however, there are many existing resources from which these hospitals can benefit.

Opportunities to help New York State hospitals identify and access the resources that would be most relevant to their issues, experience, and performance include:

- Create a roadmap to help hospitals understand the process and evolution of developing effective partnerships with PFAs.
- Develop self-assessment tools to help hospitals understand where they are in the process of developing effective, sustainable partnerships with PFAs and identify areas of strength and opportunity.
- Develop an online catalog of existing resources, categorized by (1) level of PFAC development and (2) common issues or challenges (e.g., recruitment) faced by PFACs.

“We need to accommodate different levels and needs of hospitals as they develop PFACs; not everyone is ready for the highest level.”

—Administrative Coordinator



## Recommendations (continued)

### Conduct Additional Research About the Evolution and Impact of PFACs and Expand Work to Other States and Settings

Based on its original goals, this research project provides important data about PFACs in New York State. However, many of the study findings related to PFAC best practices and impact have application beyond New York State. In addition, as hospitals and health systems acquire ambulatory practices, and as federal initiatives, such as the Transforming Clinical Practice Initiative and Comprehensive Primary Care Plus, encourage partnerships with PFAs, there are opportunities to conduct similar research related to PFACs in the ambulatory setting.

There also are opportunities to conduct research to further explore the findings suggested by this study; for example:

- **Investigate the building blocks, steps, or stages in PFAC development** to better understand the evolution process of PFACs. This could be done broadly for all hospitals or specifically for subsets of hospitals, like critical access.
- **Identify examples where lower-performing PFACs have transformed into high-performing PFACs** to highlight elements and factors that contribute to this progression.

“It is wonderful to watch the PFAs grow...they start out being uncertain and seeing themselves only in the patient role, but over time, they just bloom and define themselves as true advocates.”

—Staff Facilitator for a Behavioral Health PFAC

- **Research the mechanisms by which PFACs influence hospital leadership, strategy, operations, and outcomes.** There is still a dearth of data showing the impact of partnerships with PFAs, and a lack of understanding about the mechanisms by which this impact occurs. Additional research could include following the three cohorts (high performing, lower performing, no PFAC) over a two-year period to document factors that affect influence and outcomes.
- **Determine whether there are potential causal pathways** between the presence of a PFAC, the quality of the PFAC, and improved hospital performance.
- **Design research targeted to nonrespondent hospitals**, determining the prevalence and functioning of existing PFACs.



## Recommendations (continued)

- **Study the impact of partnerships on PFAs**—for example, investigating whether there is an impact associated with serving in a PFA role on patients' involvement in their own or their families' health and health care.

### Disseminate PFAC Study Results to Share Learnings Within and Outside of New York State

As stated earlier, there are very few prior studies that either explore characteristics and functions of PFACs or evaluate their impact. This study's findings begin to describe PFACs and key factors that support their evolution and influence and should be disseminated to key stakeholder organizations and individuals within and outside of New York State.

Potential audiences for dissemination include:

- **Policymakers**, who have the opportunity to promote partnerships with patients and families through the creation of legislation, regulation, and incentives, as well as involving patients and families in the development of national and state-level policies.
- **Public and private insurers** that can develop their own PFACs and create incentives for the implementation of PFACs at the hospital level.
- **Hospital associations and HIINs** that can support hospitals in their efforts to implement and sustain effective PFACs by providing training and technical assistance support and helping to share learnings.
- **Consumer advocacy groups** that can provide direct outreach to patients and families.
- **Hospital leaders** who can provide resources and organizational support for implementing and advancing work with PFAs.
- **Hospital staff** who can serve as champions for work with PFAs and lead implementation efforts.
- **PFAs** who can build their understanding of PFAC best practices and opportunities for improvement.

Examples of specific groups within New York State with whom the study findings could be shared are shown in Table 2.



## Recommendations (continued)

TABLE 2. Potential Audiences for Dissemination of Findings Within New York State

AUDIENCES	EXAMPLES WITHIN NEW YORK STATE
<b>Policy level</b>	
National and State-level policymakers	<ul style="list-style-type: none"> <li>• Leaders of CMS quality and safety improvement initiatives (e.g., Partnership for Patients, Transforming Clinical Practice Initiative)</li> <li>• Commissioner of Health, NYSDOH</li> </ul>
Private and public Insurers	<ul style="list-style-type: none"> <li>• New York Medicaid</li> <li>• Empire Blue Cross; Anthem BC/BS; Healthfirst; Cigna; Aetna; UnitedHealthcare</li> </ul>
Hospital associations	<ul style="list-style-type: none"> <li>• Healthcare Association of New York State</li> <li>• Greater New York Hospital Association</li> <li>• New York State Association for Rural Health</li> </ul>
Consumer advocacy groups	<ul style="list-style-type: none"> <li>• Health Care for All New York</li> <li>• New York Public Interest Research Group</li> <li>• Local chapters of the National Alliance on Mental Illness</li> <li>• Local chapters of AARP</li> </ul>
<b>Organizational level</b>	
Hospital leaders	<ul style="list-style-type: none"> <li>• Local chapters of the American College of Healthcare Executives</li> <li>• New York Organization of Nurse Executives and Leaders</li> </ul>
<b>Individual level</b>	
Hospital staff	<ul style="list-style-type: none"> <li>• Staff members who provided their contact information when completing the survey</li> <li>• Staff members responsible for the implementation of PFACs</li> </ul>
PFAs	<ul style="list-style-type: none"> <li>• Members of PFACs from hospitals in the survey sample</li> </ul>

In addition to this report, other dissemination products to support outreach to specific audiences could include:

- Policy briefs to summarize key findings, including PFAC best practices;
- Sample social media postings that can be used by partner organizations to share findings;
- PowerPoint slides that can be used in presentations to showcase findings; and
- Sample press releases for New York State hospitals with PFACs to communicate findings within their institutions.



## Recommendations (continued)

Strategies for dissemination could include:

- Share findings at upcoming conferences and meetings, for example, the HRET/AHA Leadership Summit and IPFCC's 8th International Conference on Patient- and Family-Centered Care;
- Hold a webinar to share study findings that could be publicized to HIINs and their member hospitals through CMS' Partnership for Patients Initiative; and
- Convene a virtual and/or an in-person PFAC forum for all New York State PFACs to network and share ideas generated by the report.

In addition, dissemination activities could be used as an opportunity to provide examples of partnership—for example, identifying PFAs from high-performing PFACs who would be willing to share their experiences and perspectives in webinars and at conferences and meetings.

### A NEW YORK STORY: The Next Wave of PFACs

From starting a PFAC eight years ago, one hospital (part of a large health system), has moved to developing several other specialty PFACs (e.g., cancer and wellness, mother/baby). PFAs are also involved on a board-level performance improvement coordinating group as well as a president's council. For the 10th anniversary of the PFAC, the hospital is hoping to hold a retreat for self-reflection and planning—and to address the important question: "What is the next wave for PFACs?"

## CONCLUSION

Hospital PFACs are an effective way to engage patients and families—giving consumers a meaningful seat at the table in health care delivery. By describing the landscape of PFACs in New York State hospitals—both their prevalence and variations in characteristics—this research study furthers our knowledge about this important mechanism for partnering with patients and families in improvement and change. The study begins needed exploration of PFAC performance and the impact of PFACs not only on hospital strategy and operations but also on the quality and safety of care. The study also confirms and augments prior knowledge about best practices for PFACs.



## Recommendations (continued)

Sharing this research is a critical first step in expanding and strengthening PFACs in New York State. However, if PFACs are to develop more broadly and effectively, the commitment to provide support is needed at the organizational, State, and regional levels. The research study identifies and recommends a number of strategies for these efforts.

Although the research study was conducted in New York State, many of its findings related to PFAC best practices and impact have broader application beyond the Empire State.

# PFAC Initiatives and Activities

From ways to make patients and families feel welcome and engaged, to mechanisms for increasing access to information, to strategies for patient safety, PFACs in New York State are involved in a number of significant projects.

## Hassenfeld Children's Hospital of New York at NYU Langone



▲ Family advisors, clinicians, and leaders worked together to co-design a welcome book for families that clearly conveys the concept of partnership as a safety and quality strategy. ►



### Your Child's Central Line Care

Central lines, such as Medports, Broviacs and PICCs, need extra care. Your child has a \_\_\_\_\_  
Here is how we can partner to safely care for your child's central line in the hospital.

What does the care team do?	What can you do as a family?
We ask how your child prefers central line care. We encourage you to make sure:	Let the team know how your child prefers the central line is handled.
We clean our hands.	Clean your hands and your child's hands. Ask visitors to clean their hands.
We may wear masks/gloves when we touch the central line, such as when we: <ul style="list-style-type: none"> <li>Change and date the dressing</li> <li>Change and date the backflowcap</li> <li>Access and date a Mediport with a needle</li> </ul>	We wear masks if the team requests. We may ask you and your child to wear masks when we touch the central line, such as when we: <ul style="list-style-type: none"> <li>Change and date the dressing</li> <li>Change and date the backflowcap</li> <li>Access and date the Mediport with a needle</li> </ul>
We use dressings to cover the central line site (where it enters the skin). We check to make sure the dressing is clean, dry and stays in place.	Tell a nurse right away if the line becomes disconnected or the dressing is dirty or peeling.
We change and date the dressing every 7 days or when it becomes dirty or is peeling.	Avoid showers, because the central line has to be disconnected for a shower. Disconnecting the line increases the chance of infection.
We partner with you every day to give your child a bath.	Give sponge baths to your child.
We use caps with alcohol to keep the site clean.	Partner with staff to bathe your child with medicated wipes. These wipes get rid of germs on your child's skin.
To ensure safe, quality care at all times, we sometimes have a member of the team observe when your child's nurse touches or uses the central line.	Check with nurse before using soap, lotions or deodorants. These items may stop the medication in the wipes from working.

**Tell us if something does not look or feel right. We will listen to your concerns.**

Thank you for partnering with us in your child's safe care.

▲ Family advisors and clinicians co-designed patient and family education materials about safe central line care.

### About this book

When your child is in the hospital, you need practical information and answers to your questions, like:

"How can I support my child?"

"What questions are important to ask the doctor?"

"Where can I get a cup of coffee and take a break?"

Staff and families created this book to help you find the things you need and introduce you to your child's care team.

Most important, this book shares ways we can partner with you to help your child get better.

Every section of the book includes space for you to write down your observations and make notes.

# 1

#### Welcome

Information about our philosophy of care and what to expect at the hospital.

- Our principles of partnership.....7
- Helpful things to pack.....10
- Food and dining.....14

# 2

#### Partnering with You

Some of the many ways we partner with you in your child's care.

- Getting to know you and your child.....19
- Getting to know your care team.....20
- Tips for partnership.....32

# 3

#### Your Child's Safety

Information about our commitment to your child's safety.

- Medical emergencies in the hospital.....42
- Preventing falls.....43
- Medication safety.....44

# 4

#### Your Child's Comfort

Information about our commitment to your child's comfort.

- Your child's comfort during procedures.....52
- Comfort tips for different ages.....54
- Comfort and well-being for families.....58

# 5

#### Going Home

Things to know and do so you feel ready to go home with your child.

- Going home checklist.....6
- Billing and finances.....76
- Business card holders.....82



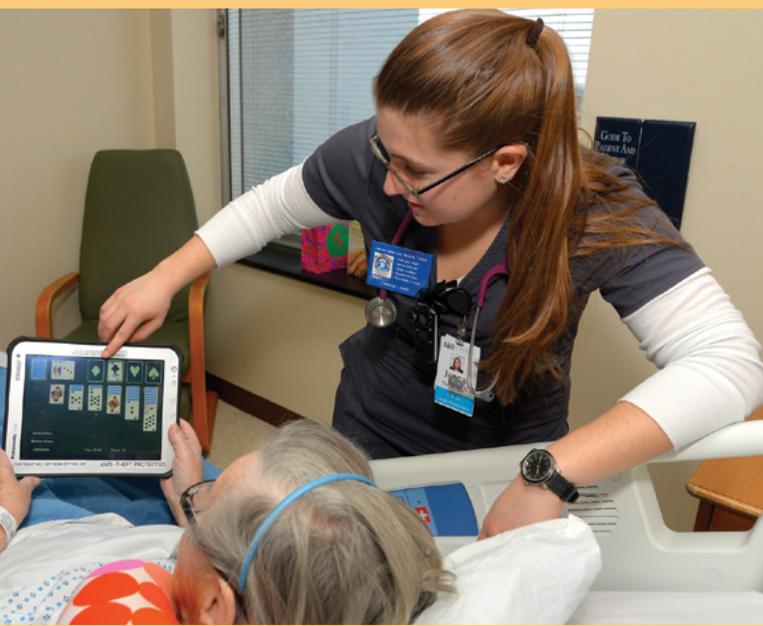
▲ Teen advisors brainstormed with program leaders to design smartphone apps to coordinate and manage care.

# PFAC Initiatives and Activities (continued)

## Northern Westchester Hospital



▲ Patient and family partners worked together with the hospital's industrial engineer to redesign the mother/baby services, and they will participate in interviewing nurses applying to work on the unit.



▲ PFAC helped with content design of the Patient Access Tablet, which offers patients a way to view their personal clinical information, in a patient-centered, user-friendly format, at the bedside.

Hospital leadership sought the advice of the PFAC about the role that integrative medicine should play within the services the hospital offers. ►

### *It's as easy as* **ABCDEF**

#### ICU Ventilator and Delirium Protocol

Learn about our evidence based protocols ABCDEF and the use of patient/family diaries to personalize, demystify, and humanize the intensive care experience. These efforts help to reduce the incidence of post intensive care syndrome (PIC enhance memory



**Northern Westchester Hospital**  
Northwell Health®

### While in the Intensive Care Unit

#### **AWAKENING TRIA** LEVEL OF SEDATIO

The patient must be in on a ventilator. However for all patients to be cc and asleep. Different p. different levels of alertn These levels can chan; patient's time on the ' may give the patient a (break from sedation) t are ready to come off t

#### **BREATHING TRIA**

The staff will continua ability to breathe on th are still connected to t patient is different in tl to be weaned off the b

#### **CHOICE OF SEDAT and ANALGESIA**

There are various types analgesic (pain) medic doses that are admir medications allow th and reduce pain while

#### **DELIRIUM**

Ventilated patients are delirium. This is a comi the ICU setting. Deliri; serious disturbance in r results in confused thi awareness of surround can include agitation, r lethargy and withdraw may experience long impairment (difficult



▲ Patient partners and the intensive care committee developed a brochure to orient patients and families to the ICU and explain in understandable terms the ventilator and delirium protocol.



# PFAC Initiatives and Activities (continued)

## Strong Memorial Hospital



▲ A member of the Department of Psychiatry Advisory Council of Consumers (DPACC) shares her experiences and insights in classes for new nursing staff supporting culture change in mental health services.



▲ PFAC members collaborate with clinicians in the implementation of OpenNotes and MyChart, enhancing patients' access to their clinical information.



### **CPEP Patients, Families and Visitors**

**We generally have the following items available to you. Please let staff know if you would like any of the following:**

- |                                     |                            |
|-------------------------------------|----------------------------|
| <b>Foam Earplugs</b>                | <b>Blankets</b>            |
| <b>Limited Snacks/Beverages</b>     | <b>Phone Availability</b>  |
| <b>Reading Materials</b>            | <b>Games/Cards</b>         |
| <b>Limited Personal Care Items</b>  | <b>Coloring Supplies</b>   |
| <b>Hospital Maps/Directions</b>     | <b>Tissues</b>             |
| <b>Nicotine Replacement Options</b> | <b>Cell Phone Chargers</b> |

**If there is anything else that would be helpful to you, please let us know and we will do our best to accommodate you.**



▲ DPACC members provided specific recommendations to improve the waiting space and first impressions for patients, families, and visitors in the Comprehensive Psychiatric Emergency Program (CPEP). The sign they created highlights some features to enhance comfort in this area.



# Appendix

## KEY ACRONYMS AND DEFINITIONS

- **PFAC (Patient and Family Advisory Council)**

A formal group that meets regularly for active collaboration among hospital leaders, clinicians, staff, and patient and family advisors on policy and program decisions.

- **PFA (Patient/Family Advisor)**

Patients and families who work together with health care professionals to improve health care. Advisors share their insights and perspectives about the experience of care and offer suggestions for change and improvement. Advisors may serve on hospital PFACs and/or other committees, task forces, and groups.

- **PFCC (Patient- and Family-Centered Care)**

Patient- and family-centered care 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. ([www.ipfcc.org/about/pfcc.html](http://www.ipfcc.org/about/pfcc.html))

- **PFE (Person and Family Engagement)**

Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care.<sup>16</sup>

- **Staff Liaison**

Individual whose responsibilities with a hospital or health system include supporting PFAs in having direct input and influence on policies, programs, and practices that impact care and services.

## TABLES

TABLE 3. Description of PFAC Indices

INDEX	ITEMS IN INDEX	RANGE	MEAN SCORE
Structure	<p><b>Does PFAC have:</b></p> <ul style="list-style-type: none"> <li>• A charter or bylaws</li> <li>• Annual written goals</li> <li>• Annual written budget</li> <li>• A PFA as a chair or co-chair</li> <li>• A senior hospital leader as an executive champion</li> <li>• A designated staff liaison</li> <li>• A defined place on hospital's organizational chart</li> </ul>	0 – 7	4.5

continued ►

<sup>16</sup> Carman, K.L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., Sweeney, J. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Affairs* (Millwood). 2013 Feb; 32(2): 223–31.



## Appendix (continued)

TABLE 3. Description of PFAC Indices (continued)

INDEX	ITEMS IN INDEX	RANGE	MEAN SCORE
Orientation	<p><b>The PFAC provides:</b></p> <ul style="list-style-type: none"> <li>• A formal orientation</li> <li>• Additional training for special PFA placements</li> <li>• Opportunities for continuing education</li> </ul>	3 – 12	7.4
Operations	<p><b>The PFAC has:</b></p> <ul style="list-style-type: none"> <li>• An agenda for each meeting</li> <li>• An agenda that is developed collaboratively with PFAC members</li> <li>• Minutes for each meeting</li> </ul>	1 – 4	3.2
Evaluation	<p><b>The PFAC:</b></p> <ul style="list-style-type: none"> <li>• Conducts an annual evaluation reviewing PFAC effectiveness</li> <li>• Conducts an annual self-assessment of member perception of participation</li> <li>• Writes an annual report</li> <li>• Provides annual report to hospital board of trustees</li> <li>• Documents outcomes of activities/initiatives</li> </ul>	0 – 5	2.1
Membership Support	<p><b>The PFAC supports meeting participation by providing:</b></p> <ul style="list-style-type: none"> <li>• Language/translation services</li> <li>• Option of participating virtually</li> <li>• Childcare</li> <li>• Parking</li> <li>• Transportation</li> <li>• Food for meetings</li> </ul>	0 – 6	2.4
Membership (includes hospital leaders, physicians, and staff members)	<p><b>The PFAC has membership representation from:</b></p> <ul style="list-style-type: none"> <li>• Hospital leadership</li> <li>• Physicians</li> <li>• Nurses</li> <li>• Direct care staff</li> <li>• Other staff</li> </ul>	1 – 5	3.8
Integration into Committees	<p><b>PFAC members serve on which committees:</b></p> <ul style="list-style-type: none"> <li>• Patient experience</li> <li>• Quality</li> <li>• Safety</li> <li>• Facility design</li> <li>• Health information technology</li> <li>• Patient and family education</li> <li>• Orientation and continuing education for staff and providers</li> <li>• Education of students and trainees</li> <li>• Research</li> <li>• Diversity and inclusion</li> </ul>	0 – 10	2.9



## Appendix (continued)

TABLE 4. Correlations Between Indices and Key Survey Variables

	Structure	Orientation	Operations	Membership	Membership Support	Recruitment	Evaluation	Reporting	Committees	PFAC Influence
Structure	1.00									
Orientation	0.57***	1.00								
Operations	0.40**	0.41**	1.00							
Membership	-0.00	0.16	-0.01	1.00						
Membership Support	0.23†	0.28*	0.13	0.27*	1.00					
Recruitment	0.49***	0.53***	0.25†	0.08	0.22†	1.00				
Evaluation	0.27*	0.40**	0.27*	0.00	0.33*	0.14	1.00			
Reporting	0.01	0.31*	0.06	-0.05	0.01	0.28*	0.15	1.00		
Committees	0.38**	0.57***	0.16	0.29*	0.33**	0.38**	0.12	0.14	1.00	
PFAC Influence	0.26†	0.52***	0.20	0.02	0.26*	0.21	0.35**	0.23†	0.44***	1.00

†p<0.10, \*p<0.05, \*\*p<0.01, \*\*\*p<0.001

n = 59, includes respondents whose hospital had a PFAC and who answered at least 50% of items for each index and provided an answer for the influence criterion validity variable.



## Appendix (continued)

**TABLE 5. Comparison of Hospitals in the Survey Sample with Hospitals Outside of Sample**

Characteristic	Hospitals in Sample (n = 90)	Hospitals Not in Sample (n = 83)
<b>Patient Age (%)</b>		
0 – 17	11.3	11.7
18 – 29	13.2	12.3
30 – 49	23.1	18.6*
50 – 69	25.8	26.0
70 or older	26.4	31.4
<b>Patient Gender (%)</b>		
Female	57.2	55.5
Male	42.8	44.5
<b>Race (%)</b>		
Black	10.1	11.7
Multiracial	0.5	0.7
Other	18.4	12.0*
White	71.0	75.7
<b>Ethnicity (%)</b>		
Multiethnic	0.9	0.05
Not Hispanic	81.8	86.4
Hispanic	11.0	7.9
Other Ethnicity	6.2	5.7
<b>Admission Reason (%)</b>		
Emergency	67.1	57.2*
Elective	17.3	28.4**
Other	15.5	14.4
<b>Condition Severity (%)</b>		
Extreme	3.6	4.1
Major	17.5	20.5
Minor	38.5	32.5**
Moderate	40.5	42.9
<b>Mortality Risk (%)</b>		
Extreme	3.3	3.6
Major	11.7	13.7
Minor	65.5	59.8
Moderate	19.5	22.9*
<b>Primary Insurance (%)</b>		
Medicaid	32.6	29.6
Medicare	37.3	43.3
Private	21.0	21.0
Other	9.0	6.2
<b>ER Admission (%)</b>		
No	39.2	48.1*
Yes	60.8	51.9*
<b>Average Length of Stay in Days [mean (SD)]</b>	5.2 (2.3)	6.7 (6.0)*
<b>Birth Weight in Grams [mean (SD)]</b>	3293.5 (166.5)	3288.4 (110.3)
<b>Charges [mean (SD)]</b>	\$24,421.0 (\$17,482.9)	\$25,556.8 (\$22,767.8)
<b>Cost [mean (SD)]</b>	\$11,196.4 (\$5,377.3)	\$11,002.3 (\$8,732.8)

\*p<0.05; \*\*p<0.01

Only included hospitals with at least 20 observations per demographic characteristic. Additionally, children's hospitals were not included in the demographics data.



## Appendix (continued)

**TABLE 6. Description of All Survey Respondents**

Characteristic	[n(%)]
<b>Is your hospital part of a multihospital system?</b>	
Yes	88 (80.0)
No	22 (20.0)
<b>Does your multihospital system have a PFAC?</b>	
Yes	33 (30.0)
No	40 (36.4)
In Development	6 (5.5)
<b>Does your hospital have a PFAC?</b>	
Yes	62 (59.1)
No	30 (28.6)
In Development	13 (12.4)

**TABLE 7. Comparison of Hospitals with PFACs, without PFACs, and those with PFACs in Development**

	Hospitals with PFAC (n = 54)	Hospitals with No PFAC (n = 27)	Hospital with PFAC in Development (n = 12)
<b>Patient Age (%)</b>			
0 – 17	13.7	10.2	19.6
18 – 29	15.2	9.1	14.8*
30 – 49	26.4	18.9	23.6†
50 – 69	25.9	27.7	24.0
70 or older	18.9	34.0	26.5**
<b>Patient Gender (%)</b>			
Female	57.7	56.6	53.3
Male	42.3	43.4	46.7
<b>Race (%)</b>			
White	62.6	74.4	76.2
Black	11.5	10.3	5.7
Multiracial	0.7	0.0	2.5
Other	25.2	15.2	15.6
<b>Ethnicity (%)</b>			
Hispanic	15.4	8.3	13.0
Not Hispanic	78.3	82.7	77.8
Multiethnic	1.3	2.5	0.1
Other Ethnicity	4.9	6.5	9.1
<b>Average Length of Stay in Days (mean)</b>	5.4	4.5	5.9
<b>Average Charges (mean)</b>	\$30,394.2	\$22,773.5	\$18,514.7†
<b>Average Costs (mean)</b>	\$12,131.1	\$10,343.7	\$10,382.5
<b>Number of Beds (mean)</b>	440.2	278.0	284.0
<b>% Critical Access</b>	3.2	10.0	23.1*
<b>% in Rural County</b>	4.8	23.3	46.2***

†p<0.10; \*p<0.05; \*\*p<0.01; \*\*\*p<0.001

Note: Includes only hospitals with at least 20 observations per demographic characteristic. Children's hospitals were not included in the demographic data.



## Appendix (continued)

TABLE 8. Frequencies of PFAC Variables (%)

	Yes	No
<b>Structure</b>		
PFAC has a charter	81.0	19.0
PFAC has written goals	64.9	35.1
PFAC has a budget	31.0	69.0
PFAC has a patient/family member as chair or co-chair	54.8	45.2
PFAC has a staff champion	93.6	6.5
PFAC has a staff liaison	95.2	4.8
PFAC has a defined place on the hospital's organizational chart	23.2	76.8
<b>Operations</b>		
PFAC meets at least 10 times/year	50.0	50.0
PFAC meetings have an agenda	3.3	96.7
PFAC meetings have an agenda that is developed collaboratively	19.7	80.3
PFAC records minutes for each meeting	10.0	90.0
<b>Membership</b>		
At least 50% of PFAC members are patients or family members	65.6	34.4
PFAC has representation from:		
Hospital leaders	93.5	6.5
Doctors	61.3	38.7
Nurses	80.7	19.4
Hospital staff	61.3	38.7
Membership is representative of patient population in terms of:		
Race	64.5	35.5
Language spoken	62.9	37.1
Age	72.6	27.4
Gender	72.6	27.4
Socioeconomic status	59.7	40.3
Health conditions	74.2	25.8
<b>Membership Support</b>		
Transportation provided	14.5	85.5
Virtual meetings available	33.9	66.1
Childcare provided	4.8	95.2
Parking provided	79	21
<b>Recruitment via:</b>		
Staff referral	95.2	4.8
PFA referral	54.8	45.2
Hospital social network	6.5	93.6
Hospital website	30.7	69.4
Hospital publications	25.8	74.2

continued ►



## Appendix (continued)

TABLE 8. Frequencies of PFAC Variables (%) (continued)

	Yes	No
<b>Orientation</b>		
A formal orientation is provided	18.3	81.7
Additional training for special PFA placements is provided	50.0	50.0
There are opportunities for continuing education	55.2	44.8
<b>Serving on Committees</b>		
PFAC members serve on the following committees:		
Patient experience	64.5	35.5
Quality	38.7	61.3
Safety	33.8	66.1
Facility design	30.7	69.4
Health information technology	14.5	85.5
Patient and family education	38.7	61.3
Staff and physician education	22.6	77.4
Student and trainee education	21.0	79.0
Research	9.7	90.3
Diversity and inclusion	12.9	87.1
PFAC members serve on the board of trustees	1.8	98.3
There are usually at least 2 PFAs represented on each committee with a PFA	75.4	24.6
PFAs have the opportunity to serve as e-advisors	78.3	21.7
<b>Reporting and Evaluation</b>		
PFAC conducts an annual evaluation	65.0	35.0
PFAC conducts an evaluation of member perception of participation	72.9	21.1
PFAC provides an annual report to the board of trustees	80.7	19.3
PFAC documents its activities	21.7	78.3
<b>PFAC Activities</b>		
At least 50% of PFAC activities were initiated by the PFAC itself	28.1	71.9
Feedback about PFAC activities is provided	98.3	1.8
Outcomes of PFAC activities are reported to:		
Board of trustees	11.3	88.7
Hospital leadership	79.0	21.0
Hospital staff	50.0	50.0
Community via hospital website	6.5	93.6
Community via hospital newsletter	8.1	91.9



## Appendix (continued)

**TABLE 9. Comparison of PFAC and Hospital Characteristics for High- and Lower-Performing PFACs**

	High-Performing PFAC (n = 17)	Lower-Performing PFAC (n = 42)
<b>Length of PFAC Existence</b>		
<1 year	5.3	23.3*
1 – 2 years	15.8	32.6
2 – 5 years	36.8	27.9
5 – 8 years	10.5	11.6
More than 8 years	31.6	4.7
<b>Number of Beds (mean)</b>	664.8	334.1**
<b>Average Length of Stay (mean)</b>	5.5	5.4
<b>Average Charges</b>	\$33,301.90	\$29,169.90
<b>Average Costs</b>	\$12,402.00	\$12,017.10
<b>% Critical Access Hospitals</b>	5.3	2.3
<b>% Hospitals in Rural Counties</b>	10.5	2.3

\*p<0.05; \*\*p<0.01

Note: Includes respondents whose hospitals had a PFAC and who answered at least 50% of items for each index and provided an answer for the influence criterion validity variable.

**TABLE 10. Average Score of Indices by High/Low Performance Status Hospitals (Based on Committees, Orientation, and Evaluation)**

	High-Performing PFAC (n = 17)	Lower-Performing PFAC (n = 42)
Structure Index	5.2	4.1*
Membership Index	4.0	3.7
Membership Support Index	2.6	2.3
Recruitment Index	3.3	2.3**
Evaluation Index	3.0	1.6***
Reporting Index	2.1	1.5†
Committee Index	4.6	2.1**
Operations Index	3.3	3.1
Orientation Index	9.4	6.8***

†p<0.10, \*p<0.05, \*\*p<0.01, \*\*\*p<0.001



## Appendix (continued)

TABLE 11. CMS Quality and Safety Metrics by PFAC Performance Status

	High-Performing PFAC (n = 12)	Lower-Performing PFAC (n = 25)	No PFAC (n = 28)
<b>HCAHPS</b>			
Mean Rating	87.2	86.5	84.7 <sup>†</sup>
Mean Percent of Patients Who Recommend the Hospital	87.0	86.3	83.5*
<b>CMS Safety Metric Proportions</b>			
<i>C. difficile</i> infection	0.03	0.05	0.1
Pressure Ulcers	0.00008	0.0002	0.0003*
Sepsis and Septic Shock	0.05	0.07	0.14**
Surgical Site Infections (Colon Surgery)	0.22	0.39	0.52
Surgical Site Infections (Abdominal Hysterectomy)	0.42	0.42	0.75
Post-Operative Pulmonary Embolism or DVT	0.003	0.01	0.02
30-Day Hospital-Wide Readmissions	0.01	0.01	0.04**

<sup>†</sup>p<0.10, \*p<0.05, \*\*p<0.01

Note: Includes respondents whose hospitals had valid results for HCAHPS survey measures and CMS safety metrics.

TABLE 12. Linear Regression Analyses for Key CMS Quality and Safety Metrics on PFAC Status

	Coefficients		
	No PFAC	Lower-Performing PFAC	High-Performing PFAC
<b>HCAHPS</b>			
Mean Rating (n=59)	(ref)	2.03 <sup>†</sup>	3.54*
Mean Percent of Patients who Recommend the Hospital (n = 59)	(ref)	3.00*	4.21*
<b>CMS Safety Metric</b>			
Pressure Ulcers (n = 58)	(ref)	-0.0001*	-0.0001
Sepsis and Septic Shock (n = 46)	(ref)	-0.07**	-0.07*
30-Day Hospital-Wide Readmission (n = 60)	(ref)	-0.01	-0.01

<sup>†</sup>p<0.10, \*p<0.05, \*\*p<0.01

Note: Multivariable models controlled for numbers of beds in the hospital and average charges for patients in the hospital. The table reflects varied number of respondents dependent on if the respondent's hospital had valid results for HCAHPS survey measures and CMS safety metrics. Only hospitals with at least 20 observations per demographic characteristic were included.



## Appendix (continued)

**TABLE 13. Predicted Values from Linear Regression Analyses for Key CMS Quality and Safety Metrics on PFAC Status**

	Predicted Values		
	No PFAC	Lower-Performing PFAC	High-Performing PFAC
<b>HCAHPS</b>			
Mean Rating (n=59)	84.98	87.02 <sup>†</sup>	88.52*
Mean Percent of Patients Who Recommend the Hospital (n = 59)	83.21	86.21*	87.42*
<b>CMS Safety Metric</b>			
Pressure Ulcers (n = 58)	0.0004	0.00029*	0.00031
Sepsis and Septic Shock (n = 46)	0.20	0.127**	0.131*
30-Day Hospital-Wide Readmission (n = 60)	0.03	0.019*	0.021

<sup>†</sup>Significance markers reference difference from hospital with no PFAC.

†p<0.10, \*p<0.05, \*\*p<0.01

Note: Multivariable models controlled for numbers of beds in the hospital and average charges for patients in the hospital. Respondent population is the same as for Table 11.



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