

**T H E B E R Y L
I N S T I T U T E**

**PATIENT EXPERIENCE
RESEARCH REPORT**

**PFACs: Where's the Money?
The Financial Impact on Hospitals**

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FRAMING OUR INQUIRY

Since the first Patients and Family Advisory Councils (PFACs) were started in the late 1990s, more than 2,000 hospitals have launched a PFAC. In some states, such as Massachusetts, PFACs are mandated. Yet, about 60 percent of hospitals still have not adopted a PFAC.

Generally, PFACs are comprised of five to 20 patients and family members, who meet periodically with hospital staff to provide feedback and input on a wide range of issues, which could include improving the patient experience, increasing safety and enhancing the quality of care. Although PFAC impact is legendary among supporters, there are many who still don't embrace the value of PFACs. At the Institute of Healthcare Improvement (IHI) Conference in December 2013, someone shared that there were audible groans from audience members when a keynote speaker encouraged adding patients to hospital committees. It has been said that in states where PFACs are required, oftentimes, lip service is accorded the committees, who have little input or impact. Recently, there have been increasing questions about the business case for starting and sustaining a PFAC.

In many circumstances, there seems to be reluctance to include patients' viewpoints. This provided an opportunity to explore and determine how patients can have a positive impact on the bottom-line and, at the same time, build a business case for the creation and effective, sustained use of PFACs.

Over the last six months, cases have been examined of where PFACs, also known as Patient Advisory Councils (PACs), have had an impact and saved hospitals

money. With this discovery, it was also determined that the amount of money, the direct savings from PFAC suggestions, was difficult to quantify. This immediately exposed an opportunity, that everyone involved with a PFAC should consider benchmarking the status quo, which is taking a baseline measure of where things stand prior to initiating an effort. Then after implementation, results should be measured to determine impact and trends. There is a significant opportunity in tracking results and reporting on them, so management is aware of the impact, whether financial or other relevant effects.

Patient satisfaction feedback through the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) surveys has defined financial ramifications; however, in this exploration we were looking for specific patient generated ideas that have been implemented and resulted in financial savings outside of just general improvement in scores (which could be associated with numerous potential efforts).

RESEARCH PROCESS

To explore the impact of PFACs, we followed a variety of paths, first through the examination of existing data. A number of institutions have PFAC annual reports, which contain descriptions of projects, many which are available online. A review of these documents led to few metrics and little data on PFACs' financial impact.

Another avenue that we explored was work from the Partnership for Patients (PfP), which involves more than 8,000 partners, including federal agencies, private-public partners and over 3,700 hospitals operating within 26 Hospital Engagement Networks (HENs). PfP has been tracking PFACs' projects. Focused on making hospital care safer, more reliable and less costly, most of the programs, initiatives and impacts of the PFAC reports are related to improving communication, staff sensitivity and patient satisfaction with few metrics.

A survey on PFACs was also distributed through a number of listservs, posted in blogs and highlighted via organizations' emails. Sixty individuals participated in the survey, sharing their insights on the PFAC world. The survey was distributed in March 2014 and consisted of 17 questions (see Appendix).

WHAT THE DATA REVEAL

To present a clear picture of the information shared by survey respondents, we review the responses below. Following the survey report, we will explore the implications for what we discovered and the ramifications of this research on the future.

Respondent Demographics

The majority of respondents (55 percent) were affiliated with only one PFAC; however, 25 percent were affiliated with two to four PFACs. When asked how they would describe themselves, over 40 percent identified themselves as belonging to a hospital that sponsors a PFAC. About one third were patients or family members. Respondents represented 29 states and Canadian provinces.

Mandated PFAC

Although only one state (Massachusetts) mandates that all hospitals have a PFAC, 55 percent of respondents agreed on state mandates for PFACs. Nearly 25 percent said, No, and about 20 percent didn't know.

PFAC Age

Nearly 40 percent of respondents say that their PFACs are relatively new – existing for three years or less. A quarter of PFACs have been operating for four to seven years, with another quarter having been established for at least eight years or more.

PFAC Voice

Of participants who responded, nearly 35 percent said that the PFAC was an integral part of the hospital and over 40 percent indicated that the PFAC voice is oftentimes heard with PFAC suggestions adopted. Unfortunately, 25 percent said that PFAC voice is only occasionally heard with PFAC suggestions sometimes adopted.



PFAC Members

Thirty percent of PFACs have 11 to 15 members on the Council, 23 percent having 5 to 10 members and 22 percent with 15 to 20 PFAC members on Council.

PFAC Satisfaction

The majority of respondents (58 percent) are extremely satisfied with the PFAC with which they are involved. However, nearly one third are only somewhat satisfied and nearly five percent are rarely satisfied or thinking of quitting.

Where PFACs contribute

In asking the question, *in what areas does your PFAC contribute* and allowing respondents to check all that apply, the area where PFACs appear to have the most impact is communication (93 percent). This was followed by quality (81 percent), signage (77 percent), safety (76 percent), clinical areas (74 percent) and orientation (57 percent).

Metrics

Sixty percent of respondents indicated that their PFACs benchmark projects some of the time, in contrast with nearly 20 percent that never do. Only eight percent always measure the status before the project starts.

Asked if they used surveys to benchmark before PFAC projects are implemented, half of the respondents involved in PFACs have never used surveys to benchmark projects before they are implemented, compared to nearly 40 percent that have.

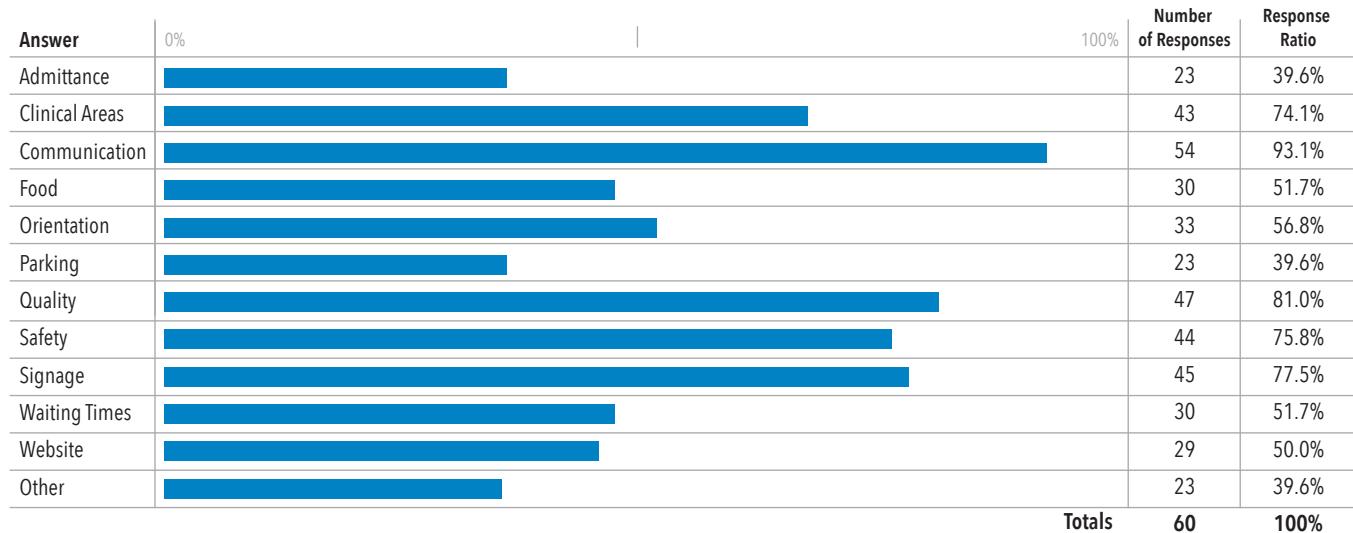
Only five percent of PFAC projects always incorporate metrics to gauge success; however, over 50 percent of respondents say that metrics are sometimes implemented. One quarter of PFACs execute projects that never utilize metrics.

Nearly half of PFACs sometimes measure the success of each project at some time after the project has been implemented; 13 percent always evaluate the progress of PFAC projects. However, nearly 25 percent never measure the success of projects.

When asked if there is a process or a procedure for implementing a PFAC project, 50 percent of respondents indicated that sometimes there is a process, 20 percent of PFACs always follow a process or procedure for execution. Unfortunately, 15 percent never use a process or procedure for project implementation.

Based on the survey responses, we found that thriving PFACs are an integral part of hospital efforts, specifically when projects are benchmarked. This includes implementing specific and measurable processes or procedures that can be tracked and followed to determine outcomes and ultimately gauge the level of impact and success. The data revealed that having a structure in place for project implementation was a key to success in effective PFAC impact, which can serve as a guiding process for many organizations struggling to establish or accelerate traction with existing efforts.

We also found that many PFACs still struggle to be heard, especially where no metrics exist either before the implementation of recommendations or after. This reinforces the need for structure as noted above and call for a reassessment of PFAC practice to ensure the best outcomes. These PFACs have an opportunity to consider alternative paths with the help of those who have worked successfully in this arena to ensure that their PFAC has the greatest impact on the hospital.



PFAC CASE STUDIES

Despite the unanimous agreement among many individuals that PFACs are important and that they provide valuable contributions, it was difficult to find statistics regarding the money a hospital has saved from a PFAC suggestion. In fact, there were a number of people who believe that PFAC ideas should not have a financial component, some suggesting that if hospitals need a business case before involving patients and family members, that a PFAC would not be successful.

Rather, interviewees pointed to industries where consumer research using surveys, focus groups and other feedback methods, contribute invaluable ideas to companies, who for decades have relied on consumers – both big and small. Disney is legendary for its children's panels, where children play with toys and watch TV shows, movies and games. Many companies will only release products and services if they've been vetted by the consumer. Yet, hospitals seem to be reluctant to ask their "consumers" questions or obtain feedback.

At Kaiser Permanente, one Patient Advisory Council liaison commented, "We would never do anything without asking the members." At Kaiser, members are integrated into many committees and have suggested hundreds of ideas that have been implemented in the hospitals, though even in this case, there were limited financial metrics.

Georgia Regents Health shared a story about chairs for patients undergoing chemotherapy. "The staff picked the chairs thinking they would be the very best for patients," related Daryl Bell, Professional Practice Leader Spiritual Care. "When patients were given the choice they picked a far cheaper version without all the bells and whistles; the patients were coming with the actual experience of chemo in mind and knew what they wanted and needed." This is a great example of the power of patient voice and the potential for true financial impact.

At Dana-Farber Cancer Institute in Boston, the PFAC suggested that afternoon food carts wasted a lot of food and suggested options that decreased the amount of waste. "PFACs have had enormous impact," stated Pat Stahl, PFAC staff liaison and manager of volunteer programs and services at Dana-Farber, which, in 1998, was one of the first hospitals to start a PFAC.

Several suggestions from the PFAC at a hospital with which Lisa Morrise has worked have saved money. One recommendation was that the intake forms include Spanish translations to avoid the need for person-to-person translator services, saving the hospital a significant amount. The PFAC also suggested an inventory

control system for clothing handed out to families in special circumstances, thereby reducing the number of disappearing clothes.

One hospital with which Ms. Morrise worked sought the Council's feedback with the question: What should the hospital give as an incentive to families who are asked to double bunk during severe respiratory season when beds are scarce? "The PFAC parents objected to the idea of giving an incentive at all," recounted Ms. Morrise, founder of LAM Professional Services. "The hospital wanted to give the double bunkers a personal DVD player (about \$75 each). However, the families suggested that it would be better to provide patients with etiquette guidelines for how to share the TV in the room." This idea saved the hospital thousands of dollars – every respiratory season.

Perhaps the idea with one of the best returns on investment was at WellSpan's York Hospital in Pennsylvania where patients were frustrated over recurring problems with billing practices. The patient advisory group suggested two letters to better explain the fees and the discount for prompt payment, although the patient involvement could not be confirmed. Prompt payments increased by six fold, boosting the net present value of the collections and decreasing collection costs.

In an example where the decision not to consult with patients and family members cost a hospital money, Darla Cohen, Coordinator of Patient- and Family-Centered Care at Riley Hospital, described an incident. "The Customer Experience Department designed, developed and implemented a Welcome Packet for all patients that did not take into account comments and suggestions made by the Family Advisory Council for our children's hospital. As a result, thousands of dollars were wasted because no one will use the packets in their current form. Input from Family Advisory Councils will inform subsequent versions."

Here's another example that Ms. Cohen described where family input was not sought in advance, resulting in an unnecessary expense. "We built a new 10-story inpatient tower and had been moving patient units in stages into the new building. Based on feedback from our advisory council and family focus groups, the surgery waiting space was located fairly close to the surgery suite area. However, it was a long, narrow room with no windows and outfitted with four televisions. When our Family Advisory Council members saw it they were appalled. The Coordinator of Patient Experience for Design and Construction happened to attend a council meeting for some other reason and was really surprised (shocked) at the extent and fervor of the negative

reaction from parents. As a result, the entire space was redesigned, at great expense, to include almost all of the recommendations of the council. Reactions from families now using the space are extremely positive."

At Stanford Hospital and Clinics, 30 to 40 Rapid Process Improvement Workshops during the year are held where patients/family members/staff and physicians do a deep dive into problems and processes. The Cystic Fibrosis PFAC worked on reducing the number of missed appointments, which wastes resources and costs the hospital money. The council found that the biggest problem was the patient's inability to get to the hospital. They put together a package with local transportation options, which is given to each patient. The results are fewer missed appointments, saving the hospital money.

At Kaiser Permanente, the National Leader for Patient & Family Centered Care Kathleen Nelson RN, MPA describes patient involvement including 400+ patient and family advisors and over 35 Patient Advisory Councils. "We have patients who shadow and round on other patients, offer peer to peer support, sit on committees, serve as faculty for new employee orientations and conferences, and co-design everything from new buildings to new processes. The results have been really incredible."

Patients and families are helping Kaiser by providing critical feedback. This improves outcomes by making care safer. "After a patient died of C. diff," continued Ms. Nelson, "we invited the patient's wife to participate in a C-diff simulation. She told us about things we said that were difficult to understand and things that scared her." That particular medical center revised its procedures and communications with C. diff patients. As a result, they have not had a case of C. diff in months. "It's very different when a patient thanks you for your important work and asks you to remember how important it is to wash your hands versus being told by a leader," said Ms. Nelson. "We've seen a boost in hand hygiene, because now we think of her every time we wash our hands."

Finally, Ms. Nelson points to staff and physician satisfaction by working in partnership with patients and families. "The staff is more energized and happier, because they are working directly with patients and families to improve care," she concluded. "This is why they entered this profession. Patients and families should be seen as equal members of the healthcare team."

Jonathan Bullock started the first PACs at Kaiser in Southern California. He is now working in Kaiser's northwest region where he has overseen the launch of five PACs in two years and is ready to start two more.

"We took a cross-section of people and seated them with leadership," said Mr. Bullock, who describes himself an evangelist of patient engagement. "Adding patient voices enhances how we provide care, including the financial piece."

In July 2014 he'll begin quarterly surveys of the Kaiser leadership to rate the value of patient advisors, so he can track what the leaders think.

IT'S NOT JUST THE MONEY

Marnie Dyer, Parent Support Coordinator at Children's Hospital of the King's Daughters, pointed out another advantage of PFACs – donated services and products. "Through the resources of our advisors, we are generally able to complete projects significantly under what the cost would have been. For example, we have a "NICU Wall of Fame" and through our advisors, we were able to secure a professional photographer who donated his services. Another advisor used her connections at a local high school to have a class construct the frames and donate the materials. One advisor is a creative director and she designs many projects and gets reduced printing."

At a Kaiser medical center, patient input also reduced falls, which have been cut by several hundred.

Amy Jones, Administrator in the Office of Patient and Family Experience, described the involvement at Vidant Health where patients and family members serve on numerous decision-making and performance improvement committees. "Patient-family advisors are so deeply embedded into our system's performance improvement work and in decision-making at all levels that we view our outcomes as being achieved in partnership with patient and family advisors. We have realized significant reductions in serious safety events and hospital acquired infections. These results would not have occurred without patient and family advisors working in partnership with us."

THE COST OF PFACS

In examining how PFACs have saved hospitals money, it's also necessary to take a look at what PFACs cost a hospital. At Stanford Hospital and Clinics, the PFACs were running on a shoe string budget. "But they were convinced to invest more based on the results that they've seen," said Joan Forte-Scott RN, MBA, the Administrative Director for Patient & Community Engagement, who does the budgets for nine advisory councils and spends less than \$100,000 a year.

Stanford has found PFACs so beneficial that the hospital is getting ready to hire a program manager. Most of the council meetings are held at night and many of the staff members are exempt employees, so little overtime is necessary. When an advisory council is started, Ms. Forte Scott guides the group for six to eight months after which a patient or member family chair is elected and, along with a staff advisor, begins managing the meetings. All the PFACs are linked through the Patient and Family Partner Program Advisory Board which Ms. Forte Scott chairs.

RECOMMENDATIONS FOR ACTION

Based on the research and interviews, we've developed 10 recommendations for starting and sustaining a successful PFAC.

- 1. Use metrics before and after implementing a project.** Without metrics the project success will be difficult to measure.
- 2. Track all projects and their results.** The success of a council is based on monitoring every project and the outcomes.
- 3. Report on results and distribute to leadership.** In Massachusetts, where PFACs are mandated, annual reports are required. Although yearly reporting is a good idea, more regular communication with leadership is recommended, so they are consistently reminded about the impact that PFACs have.
- 4. Implement all projects with a specific and proven process.** Too often projects are implemented in an ad hoc method. Every PFAC suggestion should incorporate a methodology for adoption. For example, if through a PFAC suggestion, brochures are now displayed in the waiting room, the action of photocopying and placing the brochures in their display cases should be included in someone's job responsibilities.
- 5. Recharge if the PFAC is struggling by using a guide or consultant.** According to the survey, certain respondents didn't perceive that they had a strong voice or were thinking of quitting the PFAC. Plenty of resources are available to ensure that PFACs are strong. The Partnership for Patients has a library of resources for starting and maintaining a successful PFAC.
- 6. Train PFAC members on committee participation, so they are valuable contributors.** Not everyone knows how to participate with impact in meetings. Short education sessions for current and/or prospective members should go a long way to developing valuable participation.
- 7. Involve patients and family members on all hospital committees.** Hospitals with successful PFACs don't stop with patients and family members on councils. They include patients and family members on all hospital committees.

- 8. Survey leadership about the PFACs' impact.** One of the ways to remind leadership about the existence of PFACs and gauge their opinions about PFACs is to periodically survey leaders about their impression of the councils.
- 9. Spread the word about the availability of the PFAC for research and feedback for hospital projects.** As departments become more aware of the PFAC success, they will tap the members to obtain feedback on projects.
- 10. Treat PFACs as valuable consumer research tools that can have enormous impact on a hospital's operation, safety and patient experience.** Similar to other industries, healthcare should embrace PFACs as important consumer research techniques that are necessary to ensure that the patient and family members' expectations are met and even exceeded.

IMPLICATIONS FOR FURTHER RESEARCH

Why don't more hospitals have PFACs? Lisa Morrise theorized, "Hospital administrators have said that healthcare is so complex that patients and family members can't understand it unless they have a medical degree." The goal in Phase 2 of this ongoing research is to contact senior leadership at hospitals that don't have PFACs, which is about 60 percent, and inquire about their reasons for not implementing a PFAC. This will provide the opportunity to identify and better understand the barriers and challenges to implementation.

In continuing the exploration for hard data, several hospitals have agreed to revisit previous PFAC projects and measure before and after results to tie money to the projects. Phase 2 will include metrics, before and after measurements, and concrete financial results of specific projects.

CONCLUSION

Although PFACs exist in 40 percent of U.S. hospitals, this exploration helped us discover that we still have a long way to go before the patient and family voice is heard throughout all hospitals. The data demonstrates a recognized importance and the examples outline clear and measurable impact; however, there remains a great opportunity to support and expand the case for using PFACs and to reinforce the true value that PFACs can have on the patient experience.

Daryl Bell asked, "How can we possibly make the best decisions if the people who have actually had the hospital experience aren't at the table?" Pat Stahl added, "How can a hospital NOT have a PFAC?"

That's a question worth asking.

ABOUT THE AUTHOR

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APPENDIX

Patient Family Advisory Council (PFAC) Survey

1. Are you affiliated with a PFAC?
Yes No
 2. How many?
 - a. 1
 - b. 2 to 4
 - c. 5 to 7
 - d. 7 to 10
 - e. 11 or more
 3. How would you describe yourself:
 - a. Patient/Family Member
 - b. Hospital that Sponsors PFAC
 - c. Organization that Works with PFACs
 - d. Other _____
 4. In which state are you located?
 5. Does your state mandate that hospitals have a PFAC?
Yes No Don't Know
 6. Should states mandate that hospitals have PFACs
Yes No Don't Know
 7. How long has your PFAC been in existence? (If you're affiliated with more than 1 PFAC, please average the amount of years.)
 - a. 0 to 3 years
 - b. 4 to 7 years
 - c. 8 to 11 years
 - d. Over 11 years
 - e. Don't Know
 - i. _____
 - ii. _____
 - iii. _____
 - iv. _____
 - v. _____
 - vi. _____
 8. If you are a patient or family member on a PFAC, how would you describe the PFAC voice:
 - a. Integral part of the hospital
 - b. Oftentimes heard with PFAC suggestions adopted
 - c. Occasionally heard with PFAC suggestions sometimes adopted
 - d. Rarely heard with PFAC suggestions almost never adopted
 9. How many PFAC members are on the Council? (If you are affiliated with more than 1 PFAC, then please average the number.)
 - a. 5 to 10
 - b. 11 to 15
 - c. 15 to 20
 - d. 20 to 25
 - e. 25 to 30
 - f. 31 or over
 - g. Don't Know
 10. How satisfied are you with the PFAC with which you are involved?
 - a. Extremely
 - b. Somewhat
 - c. Rarely
 - d. I'm thinking of quitting
 11. In what areas does the PFAC contribute? (Please check all that apply.)
 - a. Admittance
 - b. Clinical Areas
 - c. Communication
 - d. Food
 - e. Orientation
 - f. Parking
 - g. Quality
 - h. Safety
 - i. Signage
 - j. Waiting Times
 - k. Website
 - l. Other
 - i. _____
 - ii. _____
 - iii. _____
 - iv. _____
 - v. _____
 - vi. _____
 12. Do you benchmark each PFAC project (measure where you are before the project starts)?
 - a. Always
 - b. Sometimes
 - c. Never
 - d. Don't Know
 13. Have you used surveys to before PFAC projects are implemented?
 - a. Yes
 - b. No
 - c. Don't Know
 14. Do PFAC projects have metrics to gauge success?
 - a. Always
 - b. Sometimes
 - c. Never
 - d. Don't Know
 15. Do you measure the success of each PFAC project at some time after the project has been implemented?
 - a. Always
 - b. Sometimes
 - c. Never
 - d. Don't Know
 16. Are you aware of any PFAC projects that have saved money for hospitals?
 - a. Yes
 - b. No
 - c. If Yes, what is the name of the hospital?

 17. Is there a process or procedure for PFAC project implementation?
 - a. Always
 - b. Sometimes
 - c. Never
 - d. Don't Know
 18. Can we call you if we have additional questions?
 - a. Yes
 - b. No
 19. Comments
- First Name
Last Name
Position
Organization
Email Address

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