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Success of Patient and Family Advisory Councils: The Importance of Metrics

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Abstract

Hospital Patient and Family Advisory Councils have been around for over 40 years. Yet, their adoption is waning with only slightly more than 50% of hospitals fielding Councils, which are composed of patient and family volunteers, who provide feedback to hospital staff. Demonstrating the value of Councils is critically important to their success and sustainability. Hospitals can ensure Council success by adopting these initiatives: (1) Highlight the importance of measuring program impacts to Council liaisons and members, (2) Educate members and staff about the three types of impacts defined by the Agency for Healthcare Research Quality, (3) Describe the steps to ensure that the value of the Council is well documented, and (4) Provide tools and training for the Council and staff to conduct robust measurements and analysis. When Councils measure their impact, their value to hospitals and leadership will increase.

Keywords

patient perspectives/narratives, patient feedback, patient engagement, patient advisory councils

Introduction to the Issue

Patient and Family Advisory Councils (PFACs), which are composed of 12–25 patient and family member volunteers, meet monthly, with hospital staff to provide feedback on a wide range of issues.[1] PFACs started in the early 1980s when parents lobbied pediatric hospitals for longer visiting hours and more psychosocial support for their hospitalized children. Parent involvement moved beyond care to focus on hospital policy, practices, and facility design. As an early exemplar, Boston Children's Hospital in Massachusetts established a Parent Advisory Council in 1982, which worked for five years to help design a new pediatric facility.[2]

Over the decades, PFACs have evolved. Initially, the conversation was one way with PFAC members griping about issues. When institutions recognized that they had built-in focus groups, they began two-way conversations bringing initiatives to the PFAC for their stamp of approval. More recently, hospitals have realized that the important patient perspective could be involved in projects from the ground floor and have adopted co-designing techniques, which can have a substantial impact on hospitals.

Since 2018, the American Hospital Association (AHA) annual survey of over 6200 U.S. hospitals has included a question about PFACs: Does your hospital have an established PFAC that meets regularly to actively engage the perspectives of patients and families?[3] The most recent survey of 2021 data released in December 2022 indicates that the number of hospitals with PFACs is 51.36% down from the peak in 2019 at 55.10% with a response rate of 61.43%.

The AHA survey includes over 1300 questions. Sixty-one percent of not-for-profit hospitals reported having PFACs in 2021, compared to 32% of investor-owned or for-profit hospitals. A logistic regression analysis revealed that as the number of beds in a hospital increases, the hospital is more likely to report having a PFAC; teaching hospitals are more likely to report having a PFAC than nonteaching hospitals; and nonprofit hospitals are 1.9 times more likely than investor-owned hospitals to report having a PFAC. Twenty-three percent of responding hospitals in Wyoming and Oklahoma reported having PFACs in 2021 compared to 100% in Massachusetts, which is the only state that requires hospitals to have a PFAC.

Massachusetts' Health Care for All (HCFA), a state-wide consumer advocacy organization, shepherded the legislation which required hospitals to establish a PFAC by October 1, 2010. Although hospitals are required to provide a report upon request, HCFA collects the reports and publishes them on its website (www.hcfama.org/pfac/). They provide

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a 12-page form, which hospitals can use for their reports, and which has three questions about accomplishments/impacts:

1. What were the three greatest accomplishments/impacts of the PFAC related to providing feedback or perspective?
2. What were the three greatest accomplishments/impacts of the PFAC related to influencing the institution's financial and programmatic decisions?
3. What were the three greatest accomplishments/impacts of the PFAC related to leading/co-leading programs and initiatives?

Key Factors for Consideration

Although these three questions capture measures that might be important in helping other hospitals decide if they should launch a PFAC, they do not segment the metrics. According to the Agency for Healthcare Research and Quality (AHRQ), metrics are defined as process, which is an activity; structure, which is related to capacity; and outcome, which measures the impact. Outcome metrics are the gold standard, according to AHRQ.[4] Oftentimes, outcomes have a baseline measure or a premeasure and a postmeasure after the activity, intervention, etc, to compare the difference. In a review of Massachusetts hospital PFAC reports on the HCFA website in 2014, this author found there were no outcome measures. Likewise, in a 2022 review, no outcome measures could be identified, although there were some process and structure metrics on the number of meetings held or the training conducted, for example.

A literature search in PubMed returned 19 articles with PFAC or PFAC in the title. In a systematic review of PFAC studies in 18 articles, the authors conclude that evidence about PFAC outcomes is lacking.[5] Another study concurs that there is a "paucity of data measuring the impact of patients functioning in advisory roles," although the authors identify a number of studies with initiatives containing measured outcomes.[6(p1)] In a review of 21 articles, only six indicate the gold standard of outcomes, although others cite process and structure metrics.

Examples of outcome measures from the literature include increased health screening in a pre and postanalysis, in-patient evaluation in a pre and postsurvey, "patient satisfaction (10 to 99th percentile), decreased length of stay (by 50%), decreased medical errors (by 62%), decreased staff vacancy (from 7% to 0%), reduced patient complaints—fell from 117 in 2 month period to 48 one year—later.[6(p10–11)]

In a survey about PFACs, three hospitals had eliminated their Councils. When queried, each hospital reported that a new CEO had arrived and canceled the PFAC.[7] Presumably, the new CEO did not find compelling evidence as to why the hospital should have a PFAC. Unless hospitals adopt rigorous metrics for PFAC initiatives, the critical voice of the patient may be deleted. Further, aspiring PFACs may not find compelling evidence to undertake implementation with costs at $30,000 annually cited in one study.[8] Health systems with a high number of PFACs have turned operations over to volunteers, which decreases the financial investment.

A number of health systems have more than one PFAC, such as UCLA Health and Stanford Medicine which boast over 10. At Southern California Kaiser Permanente, 24 PFACs and specialty councils are resident at 13 medical centers. The valuable patient partnership is woven into the fabric of the organization's operations with patients sitting on many regional committees.

Recommendations

Leaders at health systems, such as Kaiser Permanente, UCLA, and Stanford, vigorously support PFACs, which is validated by their extensive use of Councils and tangible evidence of value. However, for PFACs that need to prove their value, consider these recommendations.

(1) *Highlight the Importance of Measuring Program Impacts to Council Liaisons and Members*

PFACs need to implement metrics with all the projects, which they undertake. Members and liaisons should understand the critical importance of demonstrating their value to leadership to continue to expand the PFAC influence and ensure longevity.

(2) *Educate Members and Staff About the Three Types of Impacts Defined by the Agency for Healthcare Research Quality:*

Council members and staff liaisons should be trained in AHRQ's three metrics—process, structure and outcomes—and understand how to measure each. Initiatives should have before and after measurements, when possible. Occasionally, attribution is difficult when several departments, plus the Council, work on a task; however, the PFAC involvement should be monitored and recorded with testimonials from hospital staff when metrics are elusive. In a hospital survey, only 5% of respondents indicated that they "always" use metrics and 26% said that they "never" used metrics.[9]

(3) *Describe the Steps to Ensure that the Value of the Council is Well Documented:*

Understanding the steps in proving the PFAC value includes training in defining the issue to be tackled, determining the amount of data needed, gathering the data, identifying the metric, measuring before and after the PFAC involvement, analyzing the data, and creating a visual and compelling story. Staff should keep the documentation, so it is readily available at meetings.

(4) *Provide Tools and Training for the Council and Staff to Conduct Robust Measurements and Analysis:*

PFAC staff and members should understand measurement instruments, which include surveys, financial data, and existing research. Parameters consist of time, count, and financial amount. A wide range of tools can display the results, such as run charts over time, graphs, thermometers, bubble or pie charts, etc The data analysis results should be paired with the patient's story providing the soul and the heart of the impact. For example, oftentimes, projects evolve from a patient's experience, which should be captured as an introduction to the results.

Annually, PFAC staff should submit a report to leadership about the accomplishments, which should prevent hospital leaders from dismissing PFACs, since impacts have been measured. Staff should also post an article in the hospital's internal newsletter about those successes. The newsletter article should inspire other departments to use the PFAC resources as not just a focus group, but an important co-design partner.

Conclusion

If we are to stem the decline of PFACs, we must show the value of the patient partnership. That can be accomplished by training PFAC members and staff liaisons on how to measure the process, structure, and outcome impact through robust metrics, and how to create compelling, visual stories to communicate the results. Leaders who are focused on the bottom line will easily see the PFAC return on investment. Hopefully, with Councils tracking their impact, the number of hospitals with PFACs will begin to rise again as valuable patient partnerships are integrated into hospital initiatives.

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