



PLANETREE

**Patients as Experts,  
Patients as Partners:  
*Integrating the Patient and Family  
Voice into Hospital Operations***

White Paper

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## Executive Summary

For an organization to be genuinely patient-centered, direct input from patients and families about what is most important to them about their care and how best a healthcare provider can satisfy those needs, preferences and expectations is paramount. Many patient-centered hospitals have developed Patient and Family Advisory Councils as an ongoing mechanism to solicit meaningful input and reactions from patients, families, and their community. These councils typically meet regularly to discuss opportunities for improvement within the hospital from the patient and family perspective. This can also be a very valuable group for gauging reactions to patient-centered initiatives prior to their roll-out, and for soliciting input for the refinement of existing programs. Members of such councils are poised not only to provide important feedback, but also to become knowledgeable ambassadors for the organization out in the community. However, while in theory, integration of the patient perspective is a central tenet of a patient-centered approach, in reality many healthcare providers struggle with the operational aspects of incorporating patient and family feedback in meaningful ways into hospital operations. Nonetheless, providers that espouse a patient-centered approach are obliged to find ways to overcome these barriers and to seek out multiple and varied ways to integrate patient and family voices into hospital operations. This article is a report on the proceedings of a Regional Patient and Family Engagement Forum held on June 11, 2009 and attended by staff, leadership and patients from patient-centered hospitals throughout the Midwestern United States—all members of the Planetree Membership Network, a network of likeminded healthcare organizations each at various stages of implementing the Planetree approach to patient-centered care. This article spotlights Planetree affiliates' experiences with partnering with patients as part of an overall culture of patient-centered care, the lessons they have learned along the way, and how those partnerships have yielded important results for each hospital.

## Patients' Specialized Knowledge

Patient-centered care is care that is responsive to the full scope of needs of patients and families. Fulfilling this definition requires no less than a complete transformation in how providers regard patients and families. In a healthcare delivery system in which the conventional state of affairs still finds systems designed around the convenience of providers instead of the needs of patients and families, patients can often be left to feel as if they are interlopers encroaching on increasingly time- and resource-burdened providers. This view of patients is shortsighted, though, and fails to recognize the significant expertise that patients and families can offer—not only about their own health and wellness, but also about the patient experience. Increasingly common practices like open charts, involving patients and families in rounds and change of shift report, and patient- and family-initiated rapid response teams recognize the specialized knowledge that patients and family members possess. In a patient-centered culture, though, these partnerships are not limited to the bedside, nor are they exclusively focused on an individual patient's personal healthcare needs. While, as “laypeople” patients' and families' familiarity with the complex clinical and operational aspects of healthcare delivery may be limited, their intimate understanding of the patient experience makes their involvement in hospital operations crucial.

For an organization to be truly patient-centered, direct input from patients and families about what is most important to them about their care and how best a healthcare provider can satisfy those needs, preferences and expectations is paramount. They are the reason we, as providers, exist and as such, they are our most important stakeholders. There is also a strong business case to be made for engaging with patients and families in this way, considering the heightened scrutiny on hospitals' publicly-reported performance on the HCAHPS patient experience survey.

Focus groups, patient satisfaction surveys, ombudsman programs and patient and family advisory councils (PFACs) are all staples of a patient-centered culture, and just a few of the ways that providers are tapping into the experience expertise of patients and families in order to improve delivery of care at an organizational level. However, while in theory, integration of the patient perspective is a central tenet of a patient-centered approach, in reality many healthcare providers struggle with the operational aspect of incorporating patient and family feedback in meaningful ways into hospital operations. Questions of confidentiality, limited comfort with transparency, fears that our expertise may be challenged, and concerns over what it may mean if we can't give patients everything they ask for can thwart efforts to effectively partner with patients and families. Nonetheless, as patient-centered providers, we are obliged to find ways to overcome these barriers and to seek out multiple and varied ways to integrate patient and family voices into hospital operations.

## **Patient and Family Advisory Councils: An Essential Ingredient of a Patient-Centered Culture**

Strategies for successfully and effectively involving patients and their family members at an organizational level was the topic of the Regional Patient and Family Engagement Forum co-hosted on June 11<sup>th</sup>, 2009 by Planetree and Planetree member hospital Elmhurst Memorial Healthcare. Funded by the Hulda B. and Maurice L. Rothschild Foundation, the day-long meeting drew more than 45 participants representing fifteen Planetree hospitals and healthcare systems from throughout the Midwestern United States. Attendees included staff, leadership and patient representatives, and the dialogue that ensued confirmed that while the importance of heeding the patient and family perspective is widely acknowledged, there remains much work to be done to amplify the patient/family voice to improve how healthcare is delivered.

Much of the focus of the meeting was on maximizing the effectiveness of patient and family advisory councils, and most of the participants either were currently working with a PFAC or were actively working on the development of one. For some organizations, having an active, PFAC has not only provided opportunities for constructive dialogue, but has also been a visible and vocal demonstration of a commitment to delivering care the way patients want. For others, however, establishing a PFAC and priming the organization to be responsive to its feedback is a daunting task—daunting but essential. Mechanisms like patient and family advisory councils elevate patient-centered care beyond an aspirational description of what patients should ideally expect to a culture-defining characteristic where patients are our partners in this work to deliver care in a manner that meets their needs.

Heightened recognition of the importance of PFACs is reflected in a growing collection of resources and tools available to assist sites in developing their own councils. Planetree, the Institute for Family-Centered Care, the Dana-Farber Cancer Institute and others have all developed excellent resources that sites can use to navigate their course to effective partnerships. Tools used in the absence of a sincere intent at genuine engagement with patients and families, however, will ultimately prove insufficient. With this in mind, the crux of this article will be not on specific recruitment, composition, or implementation strategies, but instead on sharing Planetree affiliates' experiences with partnering with patients as part of an overall culture of patient-centered care, lessons learned, and how those partnerships have yielded important results for each hospital.

### **Defining Partnership**

When striving to integrate the patient and family voice into hospital operations, the implications of what it means to truly *partner* are important to consider. In fact, a failure to engage with patients as partners, but instead to treat them essentially as advisors of convenience is perhaps

one of the greatest impediments to maximizing this work with patients and families. This fact was not lost on Delnor Hospital in Geneva, Illinois. With input from patients and family members serving on its council, the hospital abandoned the traditional “patient and family advisory council” nomenclature. The name it decided on—the Patient Partnership Council—emphasizes patients’ role as *partners* versus *advisors*.

When patients are integrated as partners in hospital improvement, their role is not merely to identify where improvements could be made, but also to participate in the improvement efforts. Experiences shared by attendees of the Regional Patient and Family Engagement Forum suggest that for hospitals with PFACs in their infancy, there may be a tendency to approach council members for their opinions on initiatives already well underway. Council members’ role then becomes to give their perfunctory and essentially token approval. Ultimately, such a limited role does a disservice to both the hospital and its PFAC members. The hospital has deprived itself of the opportunity to incorporate patients’ ideas early on during a project’s conceptual stages and also misses out on ideas conceived from the start by patients and family members; council members have been deprived of the opportunity to provide input of consequence.

The opportunity to play a meaningful role to improve healthcare delivery in their communities emerged consistently from patient participants at the Patient and Family Engagement Forum as what keeps them motivated to remain involved. Many are attending meetings monthly, if not more often—all on a voluntarily basis. Council members have many options of how to spend their valuable volunteer time, and as staff, it is our responsibility to provide appropriate volunteer stewardship. The most important thing we can do is ensure their volunteer time is time well spent. In the words of one PFAC staff liaison, “Advisors told us they ‘need to do more than just eat lunch.’” This desire for meaningful engagement obliges providers to ensure that their role is not a superficial one, that their ideas are thoughtfully considered, that follow-through and follow-up on suggestions is prompt, and that exchanges of information and ideas is reciprocal.

It is common for PFAC meetings to feature guest speakers from throughout the hospital. These guest speakers—be they from administration, infection control, billing, marketing, nursing, admitting, etc. —oftentimes provide education to PFAC members about different aspects of hospital operations. While ongoing education to familiarize members with how the hospital works is important, education on its own does not constitute a mutual exchange of information and ideas. To address this, Dr. Adrienne Boissy, Experience Officer for the Cleveland Clinic’s Neurological Institute and Chair of its Voice of the Patient Advisory Council, encourages speakers to come prepared with at least five specific questions or issues that they want to present to the group for feedback.

## Transparency

Partnerships are based on open and honest dialogue. Opening ourselves up, flaws and all, to patients and family members can be a daunting leap of faith, but as participants of the Regional Patient and Family Engagement Forum confirmed, one well worth taking. Dick Hanke, Patient Chair of Delnor Hospital's Patient Partnership Council, credits the hospital's commitment to transparency as one of the drivers of the council's effectiveness. "There are critical conversations that are taking place [in the council], and when they are happening with leadership, that gives you the sense that we are important to the hospital," he said.

By inviting patients and families in on these difficult conversations and soliciting their input even when things are less than ideal, partnerships are strengthened, and ultimately improvement efforts are enhanced. For Diane Ball, Delnor's Planetree Coordinator and staff co-chair of the Patient Partnership Council, transparency was not always comfortable. "The biggest thing I learned was getting comfortable with transparency and getting comfortable to listening to these stories...there was no one in that group who ever wanted that experience to happen again."

Overcoming the natural tendency to shield patients and families from challenges, obstacles or bad news may not come easily. Many organizations fear the ramifications of breaches of confidentiality, but having advisors sign confidentiality agreements is an effective way to ensure that privacy and confidentiality are maintained, while not compromising the open dialogue that characterizes a strong partnership.

### **"Don't Ask If You Don't Want Answers"**

Creating an environment encouraging of an open exchange of ideas may mean that occasionally ideas or stories from patients and family members may challenge conventional thinking. Dr. Boissy recounted the Neurological Institute's Voice of the Patient Advisory Council's experience of sharing its ideas for a new family lounge area that would best meet the needs of families and finding that the institutional vision for the space was a bit different. To ensure that the council's ideas were integrated as much as possible, Dr. Boissy shared the stories of the patients and families with designers and architects to help unite all parties around creating a more inviting, healing environment. Important lessons about how to work within the culture of the institution and how to advocate for a council can be drawn from the experience.

As Dick Hanke of Delnor Hospital's Patient Partnership Council counseled providers, "Don't ask if you don't want answers." Such a statement may strike fear in the hearts of providers, fearful of what it will mean if they can't give patients and families everything they ask for. However, in the spirit of partnership, the expectation is not that patients will ask, and hospitals will provide, but instead that patients and family members will be given the opportunity to speak

up and share their ideas, and those ideas will be considered thoughtfully, acted upon where possible, and when not possible, explanations will be provided back to council members.

While not intending to impede council members' influence or enthusiasm, Dr. Boissy advised that as the Chair of the Voice of the Patient Council, part of her role is to work with patients and family members to prioritize initiatives based not only on importance, but also on feasibility. Particularly as a council is getting up and running, early "wins" will be important for building momentum and cultivating the partnership. Elmhurst Memorial Healthcare's PFAC is in its first year of development. Sensitive to balancing the need to ensure meaningful engagement for council members and wanting to poise the council for early successes, the staff, patients and family members who comprise the council have spent the first year on discrete projects like providing feedback on a proposed new call light system, testing out a potential new patient education and entertainment system, and providing input for a service excellence curriculum for staff.

### **Patient Voices Having an Impact: Outcomes**

The impact of patient and family feedback on discrete projects like these that touch on aspects of the patient experience should not be minimized. At Delnor Hospital, the voice of one patient inspired a hospital-wide initiative. Concerned about inconsistencies observed with handwashing and gown use around patients under isolation, a patient approached the Quality Committee of the Board of Directors. His story illuminated for the board that there were opportunities to improve upon the hospital's commitment to quality, and the hospital subsequently launched Project Zero, an initiative to ensure that 100% of the time hand hygiene, isolation precautions and evidence-based medicine are practiced to prevent infections from occurring. Outcomes from the initiative have been promising: the hospital experienced one VAP infection over the course of 977 patient ventilator days; one CVC infection over the course of 4,001 device days and four MRSA infections over 42,429 patient days.

In its first year, Marymount Hospital's PFAC saved the hospital nearly \$25,000 annually. The group was asked to weigh in on the standard welcome/amenity kit provided to all new patients in order to determine what changes could be made to best meet patients' needs when they are admitted. As presented to the council, the kit contained standard items like tissues, toothpaste, a notepad and pen. Based on their personal experiences as patients or loved ones of a patient, council members discussed how most patients brought their own toiletries with them (or had a loved one bring them) and as a result, the complimentary items were extraneous. As a cost-saving alternative, they proposed offering patients a checklist of available items that would allow patients to choose any items they may need while limiting waste and redundancies.

Of course, patient and family input need not be limited to smaller-scale initiatives. On the contrary, when a hospital is planning to invest significant resources into a large project that will have an impact on patients and families, it would seem unreasonable to not solicit feedback from patients and families early on in the process. Alberta Health Services in Canada has dramatic examples of what happens when patients and families help guide large-scale facility projects.

When a children's hospital was built in Calgary in the 1970s, there was extensive discussion with the community and some families continued their involvement as a Family Advisory Council to provide ongoing guidance for pediatric services. When the new Alberta Children's Hospital was built in 2006, there was a 30 year history of collaboration and the resulting partnerships with families produced a healing environment that was very different than the original architectural proposal. While the families who were engaged to provide input knew very little about architecture itself, their stories of what did and did not work for them while they stayed with their hospitalized children provided invaluable guidance to the design team who was charged with finding workable solutions to address the issues that emerged from families. Adult family members of pediatric patients were not the only ones asked to provide input. Design workshops, gaming sessions and site tours were also used to get the unique perspectives of youths on the project.

The dramatic success of the children's hospital experience paved the way for regular input from patients, family members and citizens from the community into the development of a new health campus in Calgary in 2009 with a 40 member Citizen Advisory Team (CAT). The group meets monthly as a whole, with project-focused task forces and sub-committees meeting more frequently. Their role is to inform all aspects of the campus planning, from programs and services to the buildings themselves. Beyond the good will that has been cultivated within the community when they recognized the sincerity of the health system's commitment to integrate the patient and family perspective into its planning efforts, many very practical changes have also been implemented based on CAT feedback. CAT members pointed out that the proposed location for toilets and sinks in patient rooms did not leave room for wheelchair access from one side. They also weighed in on the need for patient lockers and shelves, the placement of overhead lighting, the location of white boards to enhance communication, and the location of stretchers in the exam rooms.

## **Beyond Patient and Family Advisory Councils**

While the focus of the June 11<sup>th</sup> Regional Patient and Family Engagement Forum was primarily on PFACs, integration of the patient and family perspectives into hospital operations is hardly limited to these councils. At Elmhurst Memorial Healthcare, two patient advisors were invited to participate on the hospital's noise reduction LEAN team, to share their perspectives as former patients about specifically what noises keep patients from resting. At Delnor Hospital, one

measure of the success of its Patient Partnership Council is the number of established hospital committees that now have a patient member. Currently, patients are among the members of 19 different committees or task forces, and many of the committee appointments were at the request of hospital personnel eager to incorporate the patient voice into the committee discussions. Among the hospital committees that now have a patient representative are infection control, ER satisfaction, nursing strategy, marketing and wayfinding. Inviting patients to participate on hiring committees is another opportunity for maximizing engagement. Having patients involved in this way not only provides valuable insights into what patients are looking for in a provider, but also conveys a powerful message to all potential hires about the organizational priorities and culture.

Leveraging patient and family members' specialized knowledge as faculty can also tremendously enhance traditional curriculums. Regional Patient and Family Engagement Forum attendee Karyl Debruyne of Spectrum Health in Michigan described how the system involves patients and family members in educating new residents. They participate in role plays, playing the part of the patient and family members as residents play the part of different members of the medical team. The live role plays are an effective way to convey the experience of care from the patient/family perspective. Patients and family members within the Alberta Health Region contributed to the development of Family-Centered Learning Vignettes, video tools used system-wide to teach staff about patient- and family-centered care concepts through the voices of patients themselves.

Since 2006, Alegent Health, an Omaha, Nebraska-based health system, has complemented patient focus groups and surveys with an ethnographic approach to understanding the patient perspective in which patients are shadowed for the full duration of their experience. This approach has been used for the system's oncology and labor and delivery services lines to ensure that the care is being delivered in a way that meets the observed needs of patients and their families.

## **Conclusion**

Healthcare providers today face a wealth of competing demands for resources and time. Accordingly, it is only natural to wonder if the investment of staff time and resources to recruit and support patient involvement at an organizational level is a wise one. For Delnor Hospital President Tom Wright, self-admittedly an initially reluctant proponent for the development of the Patient Partnership Council, the value of patient involvement considerably trumps the relatively minimal investments. "This is powerful," he said, "And something I never want to let go of, the voice of the customer, the voice of the patient."