



## Patient and Family Engagement Success Story

### Contact Information

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### Success Story

#### **Synopsis**

This story details the ambitious patient and family engagement (PFE) work undertaken by the Pennsylvania Hospital Engagement Network (PA-HEN) and the Hospital & Healthsystem Association of Pennsylvania (HAP). In 2012, HAP, as the primary contractor to the PfP, formed the PA-HEN. During the course of the PA-HEN Partnership for Patients (PfP) initiative, it became clear that in order to assist hospitals in developing an improved culture of safety, it was necessary to address the way health care is provided to patients and how to actively engage them in their care. To that end, PA-HEN/HAP became actively involved in the patient-and-family-centered-care movement. To promote the concept, PA-HEN/HAP has embarked on a journey to assist hospitals in the implementation of patient and family engagement initiatives in their facilities to provide a more consistent, high quality of care that is organized around the needs of the patient. The goal of PA-HEN/HAP involvement is to be a guiding force to assist hospitals to make patient and family engagement a reality.

#### **Your Story: Briefly tell us your story of patient and family engagement and how it helped improve safety, quality, and patient-centered care in your member hospitals.**

PA-HEN/HAP formed the first state hospital association sponsored Patient and Family Engagement Advisory Council in the United States. The council was established in August 2013 and consists of patients and family members, as well as health care professionals from across Pennsylvania, all of whom have a passionate commitment to assist hospitals and patients to come together as partners in the provision of health care. The purpose of the council is to serve as a guide and resource to assist hospitals to improve patient outcomes and patient satisfaction by the use of patient-and-family-centered-care principles. A clear goal of the PA-HEN/PFE Advisory Council is to serve as a role model for Pennsylvania hospitals. Creating a culture of collaboration and respect where everyone is valued, acknowledged and engaged is an essential element in PFE, and one which the PA-HEN/HAP Advisory Council embraces.

In addition to the larger advisory council, a sub-committee comprised exclusively of patients and family members has been established. The purpose of the sub-committee is to be certain that a forum exists for patients and family members to have a strong voice regarding issues which focus specifically on patient needs. This includes identifying issues which need to be addressed with health care practitioners and provide recommendations to the content of educational programming to address these specific issues.

Concurrent to the development of the advisory council, PA-HEN/HAP created a guidebook entitled *Patient and Family Centered Care: A key element in improving quality, safety, perception of care, and care outcomes*. The guidebook is a comprehensive on-line resource tool that provides guidance to hospitals with the implementation of patient and family engagement initiatives. It includes sections which describe the importance of patient and family engagement, identifies the role of leaders in implementing care strategies, and provides assessment tools and resources to assist hospitals to develop patient-centered care policies and procedures. The guidebook also contains case studies by PA hospitals as an example of best practices. The framework of the guidebook is the



identification of strategies which can be used by the individual, health care team, organization and community to engage users of health care services in information sharing, shared decision making, self-management and partnerships. The guidebook was distributed to all PA-HEN and HAP member hospitals, was discussed in an NCD All-HEN webinar, and has been posted on the HAP website, on PassKey, the PA-HEN collaborative website, as well as the Community of Practice (COP) website. What makes the guidebook valuable is that, although it was designed for Pennsylvania hospitals, much of it is applicable elsewhere.

A third intervention decided upon by PA-HEN/HAP was the development of an electronic PFE needs assessment survey which provides a means for hospitals to identify areas where they feel they have the greatest need for educational, networking and technical support. The survey also provides hospitals with the opportunity to share concerns, opportunities for improvement and successes as well as to volunteer to serve on the PFE advisory council or share their own best practices for possible publication in an updated guidebook. Assessment survey results have been reviewed by the advisory council in order to understand current practices which are present in PA hospitals, and it has also been used to prioritize the identified needs and to assist in the development of a plan of action to address these concerns. To date, more than 70 hospitals have completed the survey, which is still open.

***Why was change needed within your organization/what sparked the need for a new or improved program? Please provide any examples as appropriate.***

The Partnership for Patients focus on PFE has significantly helped to spark change for the PA-HEN. One of the ways in which this occurred was a recognition regarding a lack of consistent processes for ensuring patients are actively involved in and understand their care and treatment plan. As an example, to address this issue, one of the projects PA-HEN has devoted significant focus on relates to reducing readmissions. PA-HEN's Readmissions project manager makes hospital on-site visits and educates health care providers about the principles of "teach back" and health literacy. With increased understanding of and compliance in their medical regimen by patients, there will be fewer readmissions – and PFE is obviously key to that effort. As our PFE culture has evolved, hospitals and participants are seeing the benefits, which provide further momentum for this work. It simply makes sense on so many levels to involve the patient and family in their own care as part of the multi-disciplinary health care team.

When hospital leaders, health care providers, and patients and families work in partnership, outcomes are improved, patients and families report greater satisfaction with the health care experience, and health care costs are contained via fewer readmissions, reduction of litigation, and improved performance in regulatory and compliance surveys. Primarily, though, patient and family engagement is about human interactions that honor the individual and provide compassionate and personalized care.

***How did your organization implement the PFE program that is responsible for this success story? (e.g., what department or individuals championed this program? What approvals were needed? What specific actions were taken? Were there costs involved?)***

PA-HEN and HAP Leadership have both championed the PFE initiative. There are currently 27 members of the PA-HEN/HAP PFE Advisory Council. Member recruitment for both providers and patients/families consisted of email invitations, referrals from health care providers and prior patient/family involvement in PA-HEN projects. A member of the PA-HEN also visited several hospital-based PFE advisory councils in order to understand their issues and the problems they were addressing.

Regular PA-HEN/HAP council meetings provide the opportunity for provider members to hear the stories and concerns of patients and families. A very important aspect of the work has been the development of an infrastructure of education and support. Patient recommendations for education have centered on effective two-way communication between providers and patient/families. The council is currently working on the development of educational events such as offering regional summits to Pennsylvania hospitals to teach the principles of PFE, the development of video vignettes and webinars, as well as the use of social media and an



online tool kit. There are many venues to utilize in an educational process, and the key is to be creative in the approach.

The advisory council has been invited by HAP to assist in its development of a more consumer-friendly web site. Utilizing input from the PA-HEN/HAP advisory council, patients and families in Pennsylvania will find that they have greater access to applicable information and resources regarding their health care.

In the past months, PA-HEN/HAP has been approached by two individuals from two different states who are interested in starting state-wide PFE advisory councils which would be affiliated with their own state hospital associations. One of them received PA-HEN's name from the CEO of a national PFE organization. In addition, HAP's President and CEO was invited to participate in a national convening on PFE under the auspices of the Moore Foundation.

PA-HEN is also in conversation with an internationally known leader in the field of PFE regarding a possible collaboration. The senior leadership team of that organization recently provided a formal proposal presentation regarding field-tested solutions designed to assist PA-HEN/HAP to enhance efforts to organize care around the needs of the patient. A follow-up meeting is being planned to further discuss enhancements to the proposal.

PA-HEN/HAP is collaborating with the Pennsylvania Library Association on a new initiative called PA Forward. This involvement brings the principles of PFE directly to consumers in non-health care settings.

The PFE work is being funded as part of the PA-HEN and HAP's normal course of doing business. Funding for patient/family travel to advisory council meetings is being provided by PA-HEN.

All of these events are an indication that PA-HEN/HAP is becoming known as an innovator in the PFE movement.

***Improvement Measures: Please provide any specific measurements that you feel demonstrate care is safer.***

PA-HEN can reference improvement in the PfP PFE Measurement criteria. The average PA-HEN hospital at the baseline date of February 2013 was scoring 1.6 out of 5.0. The most recent results in March 2014 show hospitals now scoring 3.6 out of 5.0, which is a very noticeable 49% improvement in implementing PFE practices in hospitals. Success is indicated by the following improvement from baseline:

1. Prior to admission, hospital staff provides and discusses with every patient that has a scheduled admission, allowing questions or comments from the patient or family, a planning checklist that is similar to CMS's Discharge Planning Checklist (63% improvement).
2. Hospitals conduct shift change huddles and do bedside reporting with patients and family members in all feasible cases (58% improvement).
3. Hospital has a dedicated person or functional area that is pro-actively responsible for patient and family engagement and systematically evaluates (43% improvement).
4. Hospital has an active Patient and Family Engagement Committee or at least one former patient that serves on a patient safety or quality improvement committee or team (98% improvement).
5. Hospital has at least one or more patient(s) who serve on a governing or leadership board and serves as a patient representative (68% improvement).

PA-HEN's vision is continued progress toward goal achievement by monitoring assigned hospitals in CMS defined PFE scoring criteria and assist with moving their scores to contribute to achievement of at least 5% HEN-wide aggregate improvement from December 2013 scores.

***Pearls/Insights: Please describe your biggest insights about what worked and why it worked. What were the defining moments that produced these results?***

PA-HEN/HAP believes that when patients are involved in their health care, the quality of that care improves, with better outcomes and increased patient compliance. All too frequently, patients and their families find themselves thrust into an environment of mysterious and perplexing medical care that makes them feel disempowered, ignored, helpless and confused. When patients perceive respect for their autonomy and are actively engaged as partners in the health care team, they report better physical and emotional health. Family members who are involved in their loved one's plan of care become advocates and provide a support system that acknowledges the pivotal role caregivers play in the patient's comfort, safety and security. Health care professionals who are empowered to personalize the patient experience report greater workplace satisfaction, improved staff relationships, and a more cohesive working environment. PA-HEN/HAP's goal is for hospitals and patients/families to work in tandem to assure that health care is coming together in the right way to deliver the right results: better health, and greater patient, family and health care provider satisfaction.

A defining moment occurred when one of the PA-HEN/HAP's patient advisory council members, and his daughter, agreed to speak at a PA-HEN in-person educational event. This gentleman experienced a pre-hospital traumatic fall which left him paralyzed from the chest down and resulted in a lengthy hospital stay. During his extended hospitalization (acute care and rehabilitation) he suffered from five Stage IV pressure ulcers, some of which required surgical intervention to heal. This gentleman, and his daughter, spoke at a PA-HEN Pressure Ulcer Prevention Project educational event to a room full of health care providers. They shared their story about his suffering and care from a hospital-acquired condition – pressure ulcers – as well as their experience of not being afforded the opportunity to be fully active partners in his care. They felt the care was being provided to him versus with him. The story was incredibly powerful and the healthcare providers were obviously moved by hearing this patient's firsthand experience of an unplanned and untoward hospital-acquired condition. They gave him a standing ovation at the conclusion of his talk. This defining moment was a catalyst for formation of the PA/HEN-HAP advisory council. He and his wife are now active members of the PA-HEN/HAP advisory council and their insight, as well as the insight of every patient and family member has been invaluable to the work we are doing.

***Challenges and Successes: What challenges did you encounter when implementing changes? What strategies did you use to overcome these challenges?***

Creating a patient-and-family-centered culture as a core component of an organization's health care delivery system provides a strong foundation that can ultimately lead to successful outcomes for patients. Rather than a "quick fix" in order to meet regulatory standards and avoid financial penalties, patient and family engagement requires that a hospital make a long-term commitment to a change of culture with the goal of sustainability. Patient and family engagement requires a steadfast effort towards comprehensive culture change and the understanding that a change of this magnitude is gradual and not without setbacks and challenges. Senior leadership plays a critical role in driving system-wide quality improvement efforts and meaningful and sustainable change cannot occur without their full support and engagement. Organizations pay attention to what their senior leaders pay attention to, so leaders need to clearly communicate a vision and plan of action for integrating patient-and-family-centered-care into the daily operations of a hospital.

An essential component of patient-centered care is physician engagement. Most hospitals do well when physicians and other providers champion PFE principles. Strong provider engagement can lead to better patient experiences and an improved quality of patient care. When patients are fully engaged with any organization's mission and values, the impact can be felt throughout the care delivery process. Organizations that strive to meaningfully engage physicians and physician leadership in PFE are on the most direct path to deliver exceptional patient experiences and outcomes.

Barriers to patient-and-family-centered-care do exist, and they vary according to the customs and culture of the organization. Securing buy-in and engagement from staff, physicians, leadership and boards requires persistence.

Fully embracing a patient and family engagement approach to care requires significant organizational commitment of resources on an ongoing basis. It's a compilation of efforts by many individuals that allows challenges to be overcome.

***Vulnerable Populations: Vulnerable populations are defined as those who may need adjusted service because of (including but not limited to): disability status, income (payor status), race, ethnicity, language, religion, sexual orientation, veteran status, or poor access to health care services. Does your story include examples of how the needs and concerns of vulnerable populations were considered?***

Many factors contribute to racial, ethnic, and socioeconomic health disparities, including inadequate access to care, poor quality of care, community features (such as poverty and violence), and personal behaviors. These factors are often associated with underserved racial and ethnic minority groups, individuals who have experienced economic obstacles or have disabilities, and individuals living within medically underserved communities.

Consequently, individuals living in both urban and rural areas may experience health disparities. Racial and ethnic disparities in both health and healthcare persist. PA-HEN/HAP's premise is that patient-and-family-centered-care can assist hospitals and communities in addressing health disparities in the patient populations they serve. The PA-HEN/HAP's guidebook is dedicated to assisting readers in the implementation of this principle.

***Sustaining the Vision: What have you done to sustain the changes implemented? What is your vision or the hospital's future plan for engaging patients and families?***

Implementing a patient-and-family-centered-care culture demands dedication, flexibility, and a determination to nurture partnerships and relationships in order to not only develop, but to sustain a culture of patient, family, provider and community involvement. Full collaboration between all members of the team, having a common purpose and goal, open communication, trust, and respect for diversity are all attributes which PA-HEN/HAP PFE advisory council members model for our hospitals. PA-HEN/HAP's sustainability plan is based on a passionate commitment to the work we are doing. Once change has begun, it is important to remember that advancing patient- and family-centered care will remain a journey over time and not a destination.

PA-HEN/HAP's vision for the future of health care is the promotion of consistent, high-quality care that is organized around the needs of the patient. A change of such magnitude is not quickly or easily accomplished. The current health care system must be redesigned with the ultimate goal of integrating the patient and family perspective into all aspects of organizational operations. A partnership of all stakeholders with a shared commitment to working together with an end goal of ensuring that sustained, meaningful and complete transformation is achieved in order to accomplish the fundamentals of patient and family engagement is necessary. The mere existence of a shared vision can transform health care quality. Acting on the vision can revolutionize it.

***Quotes: Please provide a quote from a patient or family advisor and/or a hospital executive describing their perspectives on your story.***

"The Patient and Family Centered Model of Care is a strategy for success and excellence at every level of health care in America...particularly for patients and families. As a health care consumer...it's a no brainer! The Patient and Family Centered Model of Care is a win-win-win for me, my health care team, and my insurance company. The overwhelming benefits of implementing this model of care can be far-reaching and have a huge and meaningful ROI for hospitals and their leadership, health care practitioners and insurance providers. However, as a health care consumer, the biggest returns for me and my family are improved health outcomes and greater engagement and communication with our health care team."

-Kirsten Keyes, patient member of the PA-HEN/HAP PFE Advisory Council

"By creating its own Advisory Council of patients, family members, and hospital staff, PA-HEN/HAP is modeling precisely the kind of partnership that should be the norm in every hospital. PA-HEN/HAP galvanized the energy and



enthusiasm of the council by encouraging them to dream big and thanked them in advance for helping PA-HEN/HAP accomplish things they haven't yet imagined. With the creation of the council and the release of PA-HEN/HAP's Patient and Family Centered Care Guidebook for hospitals, PA-HEN/HAP has demonstrated its commitment to making patient engagement a reality and positioned itself as a national leader in the field."

-Carrie Brady  
CBrady Consulting

"I enjoy being part of the PA-HEN/HAP PFE Advisory Council because I am certain that our work will make a difference in the lives of the patients and families across the state, who trust us with their care. The only way to create and sustain changes in the care experience is for health providers, patients, and families to work together to improve it. The PFE Advisory Council is working to do just that."

-Marc Ruediger, PT, MS  
Director of Performance Excellence  
Magee Rehabilitation Hospital

***Commitment to Share: Please provide the names and contact information for individuals we may contact if additional information is needed. Is there an advisor or leader in your hospital who would be willing to serve as a resource for other hospitals that wish to learn from your story?***

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***Resources: Please provide examples or attach copies of relevant tools or other materials that you used to bring about change in your hospital.***

- Guidebook available: <http://www.haponline.org/quality/patient-family-engagement/>
- Survey available: <https://www.surveymonkey.com/s/WMXPK7>