Lessons Learned from a Systems Approach to Engaging Patients and Families in Patient Safety Transformation

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Background: Effective patient- and family-centered care requires a dedication to engaging patients and family members in health system redesign to improve the quality, safety, and experience of care. Provided here are lessons learned six years after establishing an infrastructure of patient and family advisory councils (PFACs) focused on improving health care quality and safety.

Context: A large regional health care system with multiple hospitals and ambulatory care delivery sites in the eastern United States adopted a systemwide approach to Patient and Family Advisory Councils on Quality and Safety (PFACQS®) in 2012.

Approach: This conceptual article describes the barriers and facilitators of adopting, implementing, and sustaining the PFACQS model across a large, geographically diffuse health system. Successful strategies that emerged include active board engagement, co-creation and mentorship by experienced patient advocates to support enhanced engagement by local PFACQS community members, and clear alignment with and line of sight on organizational quality and safety goals.

Conclusion: Implementing a robust network of PFACQS focused on improving quality and patient safety requires leadership commitment to transparency, as well as mutual respect and trust. Establishing clear guidelines, structures, and processes supports early adoption. Openness to continuous improvement and adaptations are important to program success and contribute to program sustainability.

In the last half of the twentieth century, principles of patient-centered care emerged in the context of ensuring human rights.[1,2] These principles focused on the dignity of the patient as owner of his or her own body, including the patient in decision making, and patient experience as assessed by measures of patient satisfaction.[2–4] Traditionally, patient and family engagement within hospitals and health systems was focused on strategies at the point of care delivery, such as informed consent and patient compliance with prescribed medicine use. Starting in 1978, with leadership from the Planetree organization, patient and family advisory councils (PFACs) emerged as a strategy for respecting the dignity of the patient and improving satisfaction.[5–7] PFACs are generally composed of community members who use the services of the hospital or health system for their own care or that of family members.[8–10] PFACs were established in many hospitals seeking patient and community input on a range of matters, including facilities design, comfort, respect, and other elements of patient experience.[1,11] Patient advocacy groups then began encouraging—sometimes challenging—health care systems and thought leaders to incorporate their experiences and insights on safety and quality concerns.[12–14] In 2004 the World Health Organization integrated patient and family engagement into its World Alliance for Patient Safety. This included patient advocates in leadership initiatives addressing hand hygiene, safe surgery, and the reporting of adverse events.[15] Health care culture and systems transformation leaders began to recognize the value of incorporating patient perspectives in both improvement work and culture transformation.

True partnership with patients and families requires dedication to engaging them with caregivers as partners in quality, safety, and continuous improvement of care. A systematic review of randomized controlled trials found that patient information materials were more relevant, readable, and understandable to patients when designed with patient input.[16] A report of state hospitals in New York found that facilities with high-performing PFACs (29% of PFACs) reported lower rates of pressure ulcers, sepsis, septic shock, and 30-day hospital readmissions, along with better patient experience scores, when compared to hospitals with low-functioning PFACs.[17] Hospitals with a PFAC reported better outcomes than hospitals without a PFAC on all performance measures.[17] Together, these studies suggest opportunities for engaging patients and family members in health system quality and safety activities, particularly those with patient-facing elements (for example, safety reporting). The evidence of the impact of patient and family engagement on health care systems transformation, however, remains weak. Liang et al. found that studies of strategies to engage pa-

MedStar's Patient Safety Roadmap
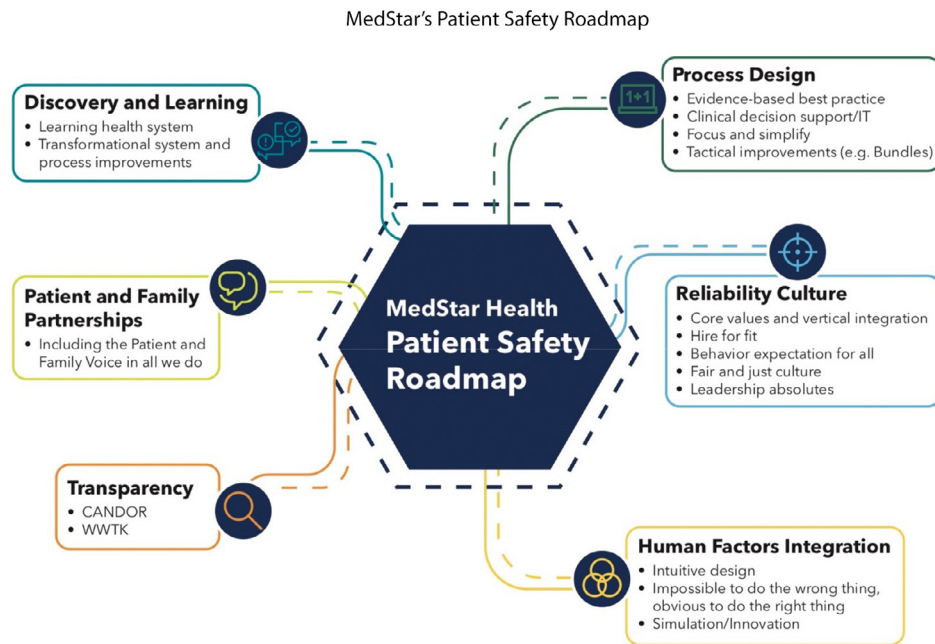
CANDOR: Communication and Optimal Resolution Program
WWTK: We Want to Know
IT: Information Technology

Figure 1: Shown are the six foundational principles (including patient and family partnerships) driving the system's efforts to achieve high reliability organization status.

tients focused more on patient involvement on committees (for example, PFACs) and less on how patient input was used or the relative influence of the patient on decisions made within these committees.[18] Factors contributing to weaknesses according to the literature include a dearth of validated metrics, diversity of organizational infrastructure for engagement, broad differences in approaches to engagement, and negative beliefs regarding patient engagement among providers.[8,14,16,18–20] A reluctance to share data on quality and safety challenges or improvement methods is a continuing impediment to effective engagement. Together, these challenges limit the strength of evidence and impede adoption of strategies for patient engagement at the organizational level.

Health systems continue to struggle to define opportunities for meaningful engagement leading to measurable change in quality and safety, culture, or operations.[18,20] There are few reports in the literature on sustained adoption of PFACs, including those committees focused on improving patient safety and health outcomes. To this end, we describe our lessons learned developing, implementing, and sustaining a scalable model of two PFACs focused on improving patient safety (defined as freedom from harm due to medical care) and quality of care (defined as the improvement of health systems services and patient health

outcomes) at a large distributed care delivery network in the mid-Atlantic United States.

CONTEXT

In 2012 our large, geographically diffuse multihospital health care system in the eastern United States made the commitment to become a high reliability organization (HRO),[21] adopting the goal of zero preventable deaths from medical error by 2020. The health system established patient and family partnerships as one of six foundational principles driving its Patient Safety Roadmap to achieving HRO (Figure 1). The integration of patient and family partnerships within MedStar's quality and safety strategy arose from its leaders' history of engagement with patient advocates in educational, research, and patient safety operational activities.[22]

APPROACH

MedStar Health's PFACQS® Model

In April 2012 the vice president for Quality and Safety led the design and development of a system-level Patient and Family Advisory Council on Quality and Safety (PFACQS®), seeking to differentiate the organization's

PFAC activities by emphasizing patient partnerships on quality improvement and patient safety activities. We convened the first system PFACQS meeting in November 2012. At this meeting we charged a steering committee of patient advocates and system leaders with developing a MedStar-wide PFACQS model. The committee reviewed PFAC best practices; made recommendations for PFACQS design, structures, and processes for implementation; and proposed measures to evaluate success. The best practices for PFACQS are listed in Sidebar 1.

The PFACQS model (Figure 2) was adopted by the board of directors in April 2013 and includes a charter and reporting relationships to the board-level Quality, Safety and Professional Affairs Committee (QSPAC), which oversees safety and quality work in the health system. The system PFACQS of experienced patient advocates reported to the vice president for Quality and Safety and the health system board. System PFACQS members included patient advocates recognized internationally as influencers of health system change.[30] Desired qualities for system PFACQS members included (1) previous demonstrated success in partnering on health system change, (2) success in pursuing legislation to improve safety, and/or (3) experience working with health system boards to influence program sustainability and structure. The model also called for hospital and ambulatory PFACQS (local PFACQS). Local PFACQS reported progress to the system PFACQS as well as to hospital and ambulatory care leadership. We established hospital and ambulatory PFACQS between fall 2013 and spring 2016.

MedStar PFACQS Implementation

In partnership with system PFACQS members [M.J.H., A.N., V.N.], MedStar created a toolkit (Sidebar 2) and provided implementation support to establish local PFACQS. The implementation team included three members of the system PFACQS, a program coordinator, and a physician
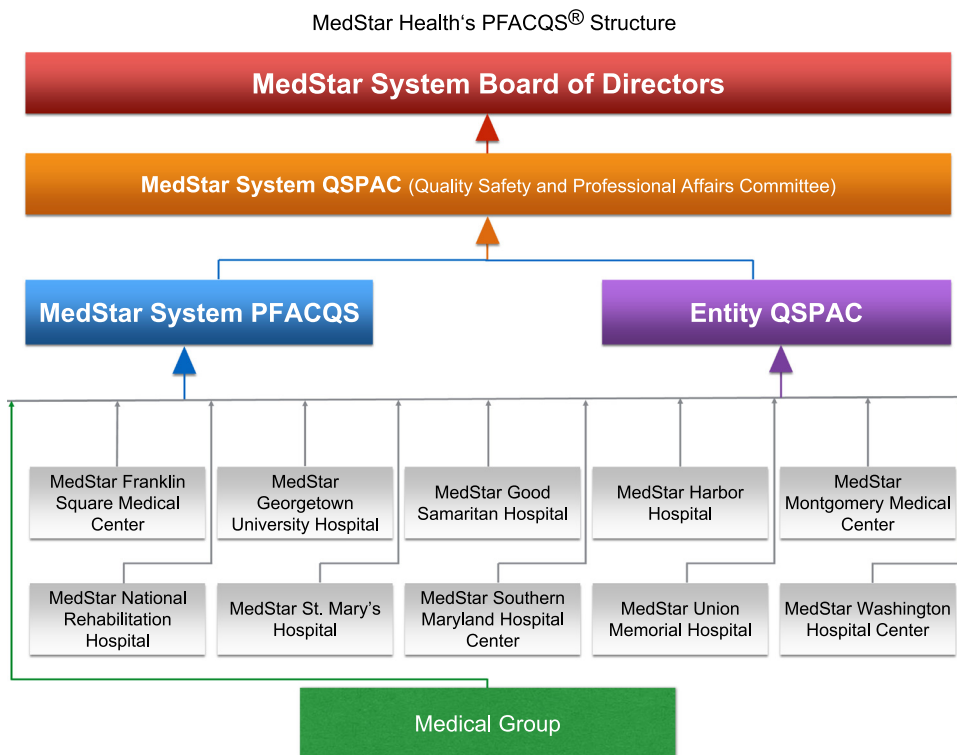

Figure 2: The Patient and Family Advisory Council on Quality and Safety (PFACQS®) includes a charter and reporting relationships to the board-level quality, safety, and professional affairs committee, which oversees safety and quality work in the health system.

Sidebar 2. Patient and Family Advisory Council on Quality and Safety Toolkit Components*

- Readiness assessment[25]
- Sample Patient and Family Advisory Council on Quality and Safety (PFACQS®) governance structure
- Staffing and membership guidelines, including guidance on appointment terms
- Community member recruitment process and sample letters
- Sample PFACQS charter adaptable to local resources
- Potential PFACQS member interview protocols and interviewing scoring worksheet
- Sustainability strategies

* Reference can be found at the end of this article.

advisor. The implementation team advised local PFACQS staff on the toolkit and conducted a readiness assessment.[25] The tool assesses readiness along several domains, including patient and family engagement in activities related to organizational culture, governance and advisory committee membership, identification of current and forthcoming strategic initiatives for PFACQS alignment, architecture and building design, patterns and processes of care, access to information, education and training, and research.

Based on the readiness assessment, the implementation team worked with the local PFACQS leaders to establish a charter, customized for each entity. They also worked with hospital and ambulatory staff to interview patients and staff volunteering to be part of the PFACQS, worked with staff to overcome implementation barriers, and attended initial kickoff meetings with each PFACQS.

A program coordinator [L.J.] and a physician advisor [R.L.] were appointed to lead the administration of the local PFACQS network, including management of the network listserv, support for local PFACQS development efforts, and regular attendance at local PFACQS meetings. The administrative staff are supported through budget line item within the Health System Quality and Safety budget.

Local PFACQS Membership

The PFACQS structure and charter advances coproduction[31] by including staff as PFACQS members working side by side with patients and family caregivers. Staff/clinician council members are functionally distinct in terms of role and responsibility to individuals responsible for PFACQS coordination. Each PFACQS is cochaired by a patient and health care team member. Representation on the PFACQS are equal in terms of numbers of patient and family representatives and health care team members. Limited terms for local PFACQS members optimize energized engagement of the community and the health care team. In addition to standing members of the PFACQS, hospital leaders, board of directors members, and managers of safety initiatives throughout the hospital and/or system are encouraged to attend PFACQS meetings. This creates a vibrant venue for

support, coaching, sharing of lessons learned, and aiding the integration of the patient voice into strategic and business planning efforts.

We recruited community members for local PFACQS through a robust, multimodal approach, including direct mailing to all recently hospitalized patients with an invitation to interview, which was tailored to reflect the community served by the hospital. This approach reaches people who are traditionally marginalized and mitigates staff bias in identifying people they perceive as good candidates. Our model also explicitly encourages recruitment of persons who have experienced patient safety events, including those who have filed complaints, grievances, or liability claims. This is a population often avoided or excluded, directly or quietly, in PFAC recruiting due to fears that their behaviors on PFACs will be motivated by anger and therefore not constructive.

PFACQS Meeting Structure

Meeting agendas are codesigned by the PFACQS cochairs (patient-staff) for both local and system councils. Leaders present key quality and safety performance indicators (hospital- or system-level) at least quarterly at the meetings. Ad hoc agenda items include progress toward the local entity's or system's strategic plan for quality and safety, updates on programs or projects by community PFACQS members, and staff presentations of upcoming or ongoing quality or safety programs requiring input. In this way, we engage the PFACQS members in both a top-down (system- or entity-directed) and bottom-up (PFACQS member–directed) approach to prioritizing quality and safety initiatives.

PFACQS Program Evaluation

Here, we describe our lessons learned in establishing a systemwide network of PFACQS. Information was collected using a variety of methods, including stakeholder interviews, review of PFACQS meeting notes, direct observations, and field notes collected during implementation. We conducted content analysis[32–35] to identify common themes emerging as central to explaining the barriers and facilitators to adoption, implementation, and maintenance of the PFACQS model.

Since the decision to adopt a patient-partnered approach to quality and safety in April 2012, all entities have adopted a PFACQS model and established 10 hospital, 1 ambulatory, and 1 health system–level PFACQS. It took just over one year for all hospitals to initiate their PFACQS. We established the ambulatory PFACQS in early 2016. Acceptability of the PFACQS model remains high across the health system. Only one hospital struggled to maintain its PFACQS due to staffing turnover. This hospital is in the process of reestablishing its PFACQS. Table 1 provides a summary of process and structure outcomes before and after PFACQS implementation through the end of our 2019 fiscal year.

Table 1. Evaluation Outcomes Before and After PFACQS® Implementation*

	Pre-PFACQS	End of FY 2019
# of Health System PFACs	0	1
# of Hospitals with PFAC	2	9
# of Ambulatory PFACs	0	1
System PFACQS		
System PFACQS Staff	0	2
System PFACQS Staff Time	0 hours/month	10–20 hours/month
System PFACQS Budget	$0	$65,000/year
System Meetings Frequency	0	quarterly
Staff per Meeting	0	10–20
System-Level Outcomes		
# of Projects Presented per Meeting	0	3–4
Local PFACQS		
Time spent on PFACQS Activities (per Staff Leader)	1.5 hours/month	1.5–15 hours/month
# of Staff PFACQS Leaders per Hospital	2	1–3
# of Patient Members per PFACQS	3	1–6
# of Staff PFACQS Members	2	3–6
Local PFACQS Budget (Total for All PFACQS)	$3,000	$30,000
Local PFACQS Support from the System		($3,000/hospital) $20,000

* The changes in outcomes cannot be individually attributable to PFACQS engagement, as it was part of a comprehensive approach to improving quality and safety (see Figure 1). PFACQS®, Patient and Family Advisory Council on Quality and Safety; PFACs, patient and family advisory councils; FY, fiscal year.

In addition to the outcomes summarized in Table 1, the organization reported a 76% reduction in serious safety events during this period. At the time of publication, all but one hospital was able to sustain their PFACQS due to staff turnover. This hospital is in the process of re-establishing their PFACQS structure.

Early implementation challenges observed by the implementation team included reluctance of some leaders to consider the importance of the PFACQS model, unbudgeted printing and mailing costs for recruitment efforts, perceived limited value of mailings to patients, existing PFAC focused solely on experience or seen as low value by leaders, and competing staff and leader priorities. The PFACQS implementation occurred concurrently with the systemwide transition to a new electronic health record vendor, increasing complexity and change fatigue. Staff turnover was a major implementation barrier. One hospital struggled to maintain staffing for its PFACQS. Strategies employed by the implementation team to overcome these challenges included engaging system PFACQS members as change agents and influencers at the local leadership level on systemwide improvement activities (for example, HRO and Communication and Optimal Resolution [CANDOR] implementations); one-to-one coaching and support for PFACQS member recruitment; non-mailing-dependent strategies for recruitment, including a town hall convened by hospital leaders and broadly disseminated to the community; and additional support for coordination of activities from the system program coordinator and physician leader.

Direct observation and attendance at regular local PFACQS meetings confirmed that hospital staff and leaders found that the PFACQS model fits with the organization's mission and values. This was also confirmed through formative evaluations during CANDOR gap analysis evaluations.[36] The appropriateness of the PFACQS model is evinced through leadership engagement and continued fiscal support for the program. Here, one member of the system QSPAC and members of the board routinely attend the quarterly meeting of the system and local PFACQS, gaining insights firsthand from the members. Our PFACQS model has spread to the programmatic level (for example, to guide cardiovascular and diabetes services), exploration of new PFACQS for research, and inclusion of patients on governance boards within the health system's institutes.

Table 1 outlines the investment of the health system in terms of staffing and financial support for the PFACQS model. First, the system invested funds to engage system PFACQS members to codesign and support implementation of the PFACQS across the health system. Second, funding for system and local staff support the management and coordination of PFACQS activities. Job descriptions now include PFACQS coordination for staff, representing between 1% and 10% full-time equivalent effort. Third, local PFACQS provide a light meal and parking vouchers for their volunteer members to support engagement. Fourth, system PFACQS members receive small honoraria and travel reimbursement for meeting attendance. Fifth, the health system supports the cost of conference services for quarterly off-site meetings necessary to accommodate both the local and the system PFACQS members and health systems leaders.

The PFACQS model was implemented as originally proposed in 2012 with few adaptations. One adaptation to the original model is establishing two communities of practice: one bringing system and local PFACQS community members together quarterly and a second monthly practice meeting for local PFACQS staff to discuss operational challenges and share emerging projects and best practices. These adaptations demonstrate the institutionalization of PFACQS within the health system. Another measure of penetration of the PFACQS model is how patients and community members are engaged in improvement activities. PFACQS members have been engaged as influencers and change agents; have initiated programs; have partnered in program design and redesign efforts; have codesigned patient materials, including brochures, awareness campaigns, training videos, consent forms, and admissions packets; and have partnered on more than 10 large-scale implementation projects as coinvestigators or codesigners. It is rare that a systemwide initiative proceeds without being presented at a PFACQS meeting to receive input from our community.

Lessons Learned

Our experience demonstrates that it is feasible to sustainably design and implement a robust network of PFACQS focused on partnership with patients to improve the quality and safety of health care delivery. Facilitators of implementation include strong institutional support for the patient-centered mission, alignment of the PFACQS activities with organizational goals and strategic plan, and active and engaged leadership. We found that although there was a clear commitment for sharing data and progress toward our goals, implementation of elements of the PFACQS— including robust and transparent data sharing—was difficult at first. Our experience has resulted in several important lessons learned for other organizations to consider.

As demonstrated by the work of the World Health Organization and informed by our own research and experiences, patient and family contributions to the patient safety mission of an organization are often catalysts for change. Yet they can be ineffective in the absence of strong institutional partnership.[15,22,36–38] System PFACQS members were engaged as codesigners of several systemwide safety programs, including HRO,[39] CANDOR[36,40–43] program implementation, our We Want to Know program for patient safety event reporting,[44–48] and most recently, advancing awareness and detection of sepsis.[49] These efforts engaged not only the system PFACQS but also local members to drive systemwide improvements in quality and safety. Together, these activities elevated the internal and external visibility of the health system's commitment to meaningful engagement, quality improvement, and zero preventable harm.

While leadership structure and best practice tools enabled rapid start-up and growth of a robust PFACQS network, willingness to adapt the model to meet local resources and organizational culture were important dimensions of success. Our commitment to learn from each implementation and share best practices transparently resulted in a PFACQS model that is adaptive. Each new PFACQS served as a learning laboratory within the health system, with lessons embraced as innovations by others. Moving from siloed entities toward a robust learning community improved perceived value, fostering sustainability. Significant shared learnings to date include strategies for active board member engagement, effective ways to communicate safety messages to patient communities, pathways for garnering resources in the planning process, and PFACQS support for staff education and behavior change activities. Together these factors helped to drive the growth and sustainability of the PFACQS across the system.

Not all PFACQS were initially successful. There was variability across the local entities in the pace and fidelity of implementation of the PFACQS model. Some hospitals moved quickly, establishing robust PFACQS, while others lagged. Barriers to implementation and sustainability included leadership changes and messaging, competing priorities, staffing and turnover, and recruiting and retaining community members. The rapid expansion of widely distributed ambulatory care settings meant adapting the PFACQS model to address challenges such as travel time due to the broad geographic region. Here, solutions such as virtual meetings were critical to success. Strategies at the hospital setting included strong and visible leadership in the implementation of PFACQS, presence at regular PFACQS meetings, and integration of feedback from patients and family members into practice transformation efforts. Additional strategies employed at the system level to support local PFACQS included creating an environment and quarterly opportunities to share learning from hospital PFACQS with system PFACQS members and coaching of local PFACQS members from system PFACQS staff and patient advocate coaches.

Limitations

There are several important limitations to this work. We have reported on the implementation of our PFACQS model in a single organization, which may not be generalizable to other health systems. Although our system represents large and small hospitals in rural, urban, and suburban locations, including both academic and community hospitals, suggesting that the model is adaptable to diverse hospital settings with variable resources for engagement, our experience with PFACQS implementation may not be generalizable. The lack of a formal evaluation of the PFACQS employing rigorous implementation frameworks is another important limitation warranting further study. We also recognize the potential for bias of the results of our implementation challenges, as the authors were also coproducers and participated in PFACQS design, implementation, evaluation, and sustainability activities. To this end, we have reported on both our successes and failures observed over the

past six years of PFACQS implementation to share lessons learned with other health systems considering an organizational approach to patient engagement.

CONCLUSION

This article shares our lessons learned from designing, developing, and implementing a network of PFACQS focused on improving the quality and safety of the care delivered within a large distributed care delivery network. Important lessons included the need for structures and processes that align with entity and system priorities to support long-term sustained PFACQS implementation. Challenges of perceived value, transparency, and trust resulted in slower implementation at a few hospitals. Strengthening supportive measures such as mentorship, coaching, and activation of additional leadership support helped to overcome these challenges. Our PFACQS model continues to evolve, remaining nimble in a time of significant uncertainty within the health care environment. By adapting and changing in response to external pressures, the PFACQS remain relevant. Future efforts for our PFACQS will be to establish clear outcome metrics and curate projects influenced by patient and family partnerships. Only in this way will organizations realize the full value and power of patient partnerships in health care transformation.

Box 1. MedStar Health Signaling Sepsis Public Awareness Campaign

Problem: Sepsis is a nationwide public health problem with more than 1.5 million Americans developing sepsis. Of these, 250,000 die of sepsis-related complications. Despite hospital level efforts to reduce the impact and mortality from sepsis, the rates of sepsis were climbing across MedStar Health.

Improving Sepsis as a System Priority: In 2016, MedStar Quality and Safety made reducing rates of sepsis as a system-wide priority and convened an improvement collaborative to identify opportunities for improvement in the sepsis care management process. The collaborative included a member of the System PFACQS®, a Local PFACQS®, and a community member, all of whom had personal experiences with sepsis. The collaborative was co-led by the System PFACQS® member, a system-level quality director, and a performance improvement leader.

Identified Gaps: The collaborative identified several opportunities for improvement to optimize compliance with national standards for sepsis identification and management. This included patient and family awareness of sepsis and how to detect it, awareness and education on sepsis recognition and response for frontline care teams, and improved reporting of local, unit-based metrics for sepsis to further raise awareness and monitor sepsis impact.

Improvement Program: The collaborative prioritized education of frontline staff and patients of sepsis as a key strategy for improvement along with improved access to Systematic Inflammatory Response Syndrome (SIRS) testing kits (including collection materials for STAT bloodwork orders) on the unit, and a general awareness campaign for all care settings (inpatient and ambulatory). The patient partners recognized that identifying the symptoms from sepsis early, while still at home, provides the best chance for receiving life-saving treatment, and pushed MedStar to conduct a broad, system-wide Sepsis public awareness campaign designed and delivered by patient members of the collaborative and the Local PFACQS®. Patient-facing materials including a video featuring the patient partners and a brochure were designed and reviewed for clarity and health literacy. The Signaling Sepsis campaign was launched in September 2016.

Evaluation: The Signaling Sepsis campaign received broad media coverage and was integrated into system-wide messaging services, a screen

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saver was pushed to all MedStar computers, and we launched a public-facing initiative home-page and mandatory education for MedStar associates. Brochures and videos were disseminated through PFACQS®, websites, and a robust social media campaign. The sepsis public awareness campaign engaged 115,381 individuals and received a total of 18,470 post engagement comments between October 2016 and October 2017. More than 27,000 brochures were distributed to patients across the region and were included in all new patient orientation packages through the Visiting Nurses Association. Between October 2016 and October 2017 compliance with national standards for sepsis treatment improved by 23%. Simultaneously, MedStar's observed to expected sepsis mortality index decreased from 1.26 to 1.04.

Box 2. Partnering with Patients to Dispel Misconceptions of Delirium

Problem: Delirium is a disturbance of mental abilities resulting in confused thinking and reduced awareness that impacts about 40% of patients over the age of 65 years and is associated with a 22% mortality for those patients who are hospitalized. Up to 70% of patients with delirium go untreated.

PFACQS® Member's Experiences Delirium: A family member of a PFACQS® member experienced delirium during a recent hospitalization. The family were confused and scared by the event. The member requested clarity on the hospital's programs and policies for delirium recognition and treatment, including information for patients and families.

Identified Gaps: The review indicated that the hospital had guidelines for identification and treatment of delirium in place, but clinicians and staff were unaware of the serious impact of delirium on patient outcomes including length of stay and mortality. No patient or family resources to prepare patients for delirium existed.

Improvement Program: Hospital nursing leaders partnered with PFACQS® members to design an educational program for clinicians and staff to improve recognition of delirium as a medical emergency. They also designed information for patients and families – the *Delirium Alert List* - to improve awareness, identification, and response to symptoms of delirium, including empowerment of, and a process for, speaking-up to the care team. A clinician/nursing toolkit included the integration of the Beers criteria into a pharmacologic reference tool for prescribing for older adults and practical clinical decision support for medications was available to clinicians and nurses on all units.

Evaluation: The Delirium project encompassed several important components to assist with education and empowerment of patients and frontline care team members. Health care providers completed mandatory training on delirium identification, assessment tools, and treatment options. PFACQS® created patient education materials. Patients received materials on delirium upon admission to the hospital. Materials about Delirium were posted in public spaces including the cafeteria and main lobby of the hospital. Other outcomes included reductions in length of stay, reduced sitter use, reduced medication use (e.g., lorazepam, haloperidol), improved documentation of delirium assessment in the electronic health records, and increased use of patient education materials.

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