



# Organizational-Level Consumer Engagement: What It Takes

Case Study: *Children's Mercy Kansas City*



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## Introduction

Person-centered, value-driven health care delivery includes patients and families as partners in all aspects of decision-making about their health care. In practice, however, most health care delivery falls far short of achieving this goal. Yet health care systems are increasingly seeing the value in engaging patients not only in direct patient care, but to guide organizational decisions about that care. And while there is growing interest among health care organizations in taking meaningful steps to improve patient engagement, there is a knowledge gap and activation barrier to achieving this change and making sure the voice of the patient is incorporated at all levels of organizational decision-making.

The purpose of this project was to learn from organizations that have made a commitment to engaging patients and families at the organizational and system levels, recognizing that even highly committed health care organizations are at varying stages of maturity when it comes to implementing structures to actualize their goals in this area. In particular, we were interested in learning with more specificity about the engagement structures organizations have employed, what it takes for organizations to operate those structures, and what has been the impact of these structures both on the organizations and on the people and communities they serve.

Interviews were conducted with staff, patients and families at three health care organizations that have undertaken concerted efforts to meaningfully engage consumers at the system level:

- Children's Mercy Kansas City
- Hudson River Health Care
- Trinity Health

The resulting case studies describe the patient and family engagement strategies adopted (or in the process of being adopted) by these organizations and estimate the resources that are needed to initiate and sustain these strategies. By sharing this level of detail, the intent is to help spur broader adoption of meaningful consumer engagement strategies by other health care providers.

*To learn more about the project's methodology and findings or to read the other case studies, please visit the [project webpage](#).*

## Terminology

*This document preferentially uses the following terms as they are defined below. Where the health care organizations studied used specific terminology to describe their objectives, activities and programs, their preferred terminology is used within their respective case studies.*

**Patient** is used as an umbrella term to represent an individual or their authorized representative – such as a parent of a minor or an adult child of an aging parent – who interacts with the health care system. A patient may also be referred to as an individual, person, consumer, member, beneficiary, caregiver or resident.

The terms **family** and **caregivers** are used in certain contexts to refer to patient-authorized individuals involved in providing care or decision-making support for a patient. Caregivers may include family members, friends, authorized representatives, community-based supporters or others authorized by the patient to support them in their care.

**Patient and family engagement** is the act of partnering with patients and families in defining, designing, participating in and assessing the care practices and systems that serve them to assure they are respectful of and responsive to individual patient preferences, needs and values.

**Person-centered and family-centered care** refer to health care planning, delivery and evaluation that sees patients, families and caregivers as equal partners in making sure care meets their goals, needs and preferences. This can also be referred to as people-centered or patient-centered care.

**Patient experience** is a component of health care quality that encompasses the interactions that patients have with the health care system.

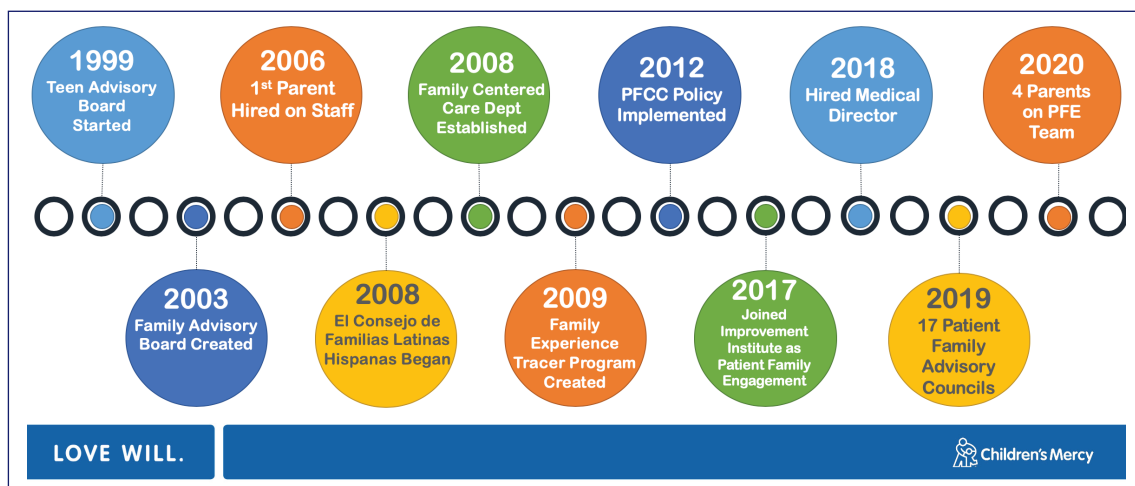
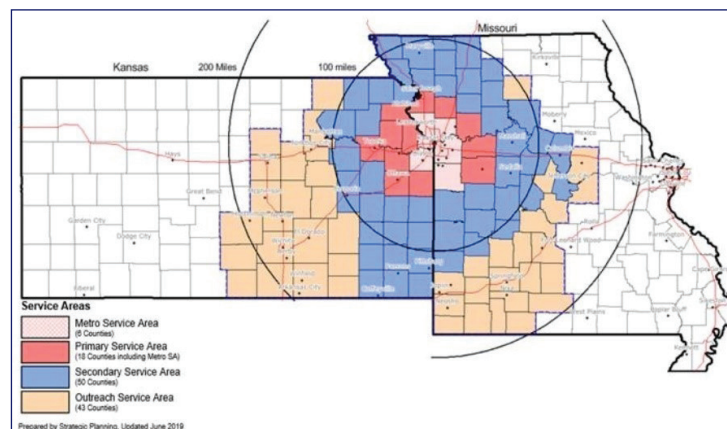
*Sources: CMS, Institute for Patient- and Family-Centered Care, AHRQ, National Academy of Medicine, Center for Consumer Engagement in Health Innovation, Health Care Transformation Task Force*



## Background

Children's Mercy Kansas City (Children's Mercy) is a comprehensive pediatric medical center founded in 1897 by the Berry sisters, a dentist and a surgeon, who were dedicated to providing care to the neediest children in the community. Children's Mercy now has more than 8,000 employees, including approximately 750 pediatric specialists. In 2018, they experienced over 600,000 outpatient visits and more than 15,000 patient admissions across their hospital campuses and multiple satellite clinics in Missouri and Kansas. Children's Mercy established its first Advisory Board in 1999. By 2012, patients and families were active participants in revising the hospital's strategic plan and mission statement, as well as in the design of a formal Patient and Family-Centered Care (PFCC) Policy delineating patient and family perspectives across the hospital's clinical, quality improvement, policy and research activities.

Children's Mercy now requires that multiple hospital committees, councils and projects include the patient and family voice. In addition to a system-wide Family Advisory Board, Latino Advisory Board (El Consejo de Familias Latinas/Hispanas), and a Teen Advisory Board, Children's Mercy has 14 department or topic-specific Patient and Family Advisory Councils (PFACs). The chart below highlights the growth of Children's Mercy engagement activities since 1999.





Children's Mercy is recognized as one of the Caregiver Action Network's 25 of the Nation's Best Practices in Patient and Family Engagement. The hospital's leadership and staff take pride in their deep-rooted devotion to patient- and family-centered care, "from hospital bed to board room." Many hospital staff and families point to their Midwestern values emphasizing "giving back" to the community and others emphasize the hospital leadership's dedication to a patient- and family-driven culture as the cornerstone of their success. This case study documents the strategies Children's Mercy applies to engage patients and families to improve quality of care for their patients. Numerous engagement outcomes are highlighted throughout the case study, including: patients and families informing the design and improvement of educational tools and resources; facilities; policies and procedures; and staff and family communication practices.

## Data Collection Methods

Twenty-one individuals provided insight into Children's Mercy patient and family engagement strategies for this case study, from those who experienced Children's Mercy's clinical care first-hand to the hospital's Chief Executive Officer who reinforces a culture of engagement system-wide. Some individuals interviewed devote the majority of their work time to patient and family engagement, including the Director of Patient and Family Engagement and the two Program Managers for Patient and Family Engagement. Others interviewed integrate patient and family engagement activities into their broader work, such as the Director of Quality Improvement and the Improvement Academy; Senior Director of Nursing, Peri-Operative Services; Director of Culture and Language Coaching; and the Senior Vice President of Ambulatory and Physician Practice Operations. Four of the individuals interviewed were hospital volunteers and parents of patients at Children's Mercy who support residency education, participate in unique administrative and clinical hospital projects, and guide policy as members of advisory boards, including the Family Advisory Board and El Consejo. In addition to these interviews, this case study was informed by the review of Children's Mercy engagement materials, including PFAC agendas and minutes, relevant journal articles, staff correspondence, training materials, strategic planning documents, and revised policies and procedures.

Patients and their families collaborated with Children's Mercy Vice President of Facilities to share valuable bathroom redesign insights that, according to the Vice President, "would have never been discovered by the architects." This is one of the many outcomes of engagement described within this case study.





## Findings

### Engagement Strategies and Structures

#### *Operations and Administration*

All of Children's Mercy patient and family engagement activities are housed within the hospital's Improvement Center, established in 2010. The Executive Director of the **Improvement Center** reports directly to the hospital's Chief Operating Officer. Children's Mercy established their **Patient and Family Engagement Team (PFE Team**, a merger of their Family-Centered Care and Patient Experience departments) in 2017 to support the hospital's infusion of the patient and family voice within all levels of the organization. The PFE Team, housed within the Improvement Center, is responsible for the oversight of all system-wide and department-specific Patient Family Advisory Councils (PFACs) and serves as the liaison between all the groups. They also provide training and peer mentoring to Patient and Family Advisors (PFAs). The PFE Team's Program Managers were hired in 2008 based upon their experience as parents of pediatric patients at Children's Mercy. This move is seen as a "game-changer" by Children's Mercy's President and Chief Executive Officer who reports that it "raised the organization to a higher standard of performance because [staff] know our family members are walking the halls and are in meetings every day." The PFE Team evolved over time to include a Medical Director who speaks Spanish and English, a Director, a Patient Experience Specialist, and two additional Patient and Family Engagement Coordinators who also are parents of patients (not pictured).

Children's Mercy Patient and Family Engagement Team (2019)



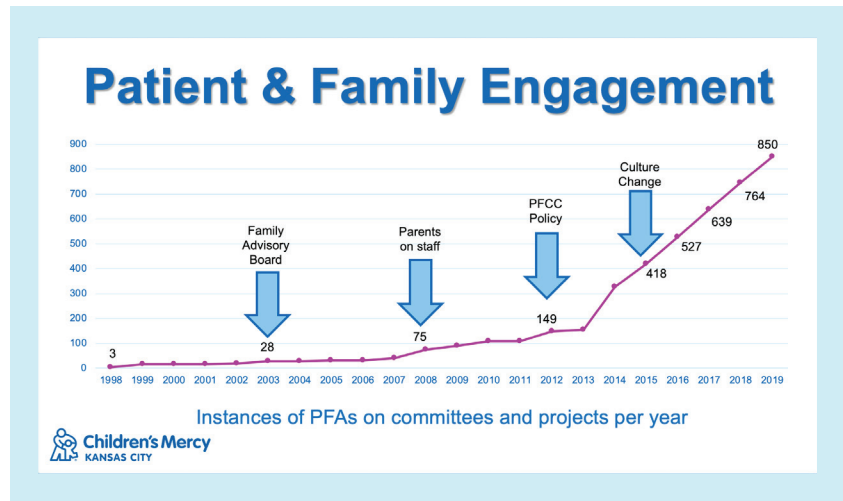
The PFE Program Managers attend numerous hospital-wide and departmental leadership meetings to provide a patient and family lens, as well as work with hospital leadership across departments to identify ways in which patients and families can be more engaged. In addition to recruiting, training and supporting the PFAs, the Program Managers also provide training to staff on how to effectively integrate PFAs into committees and projects. These Program Managers assume an important role bridging the hospital staff, patients and families – providing a safe place for everyone to ask questions and seek advice on how to improve the engagement process. Children's Mercy also employs three additional parents, not on the PFE Team, who are paid staff supporting engagement within departments or programs (the Neonatal Intensive Care Unit (NICU), tracheostomy services and peer support). These three positions were born from unique departmental needs, and in some instances, grant funding.

#### *Patient and Family Advisors*

Children's Mercy has over 200 **Patient Family Advisors (PFAs)** - volunteers who represent the patient and family voice on advisory boards, PFACs, and individual projects or initiatives. Children's Mercy uses the instances of PFA participation on committees and projects as one of their measures of engagement success. In 2003, there were 28 instances of PFAs engaged on committees and projects and in 2019 there were 850 instances. Hospital leaders point to the hiring of parents, which started in 2006, as a reason for the steady increase of PFA engagement over time. The chart below demonstrates the increase of Children's Mercy PFA engagement over the past 20 years.



Patient and Family Advisors are recruited through referrals by staff, patient advocate and social work departments, newsletters, the hospital website and community events. Prior to becoming a PFA, individuals are interviewed by the PFE Team to understand their interests and availability. The PFE Team decides who will assume the role of PFA based not only on the interview, but also recommendations from medical staff who have had previous experiences with the individual. The PFE Team selects PFAs based on the individual's availability and his/her readiness to work collaboratively with staff to improve hospital practices. Moving forward, Children's Mercy will collect data on PFAs' demographics, including race, ethnicity, socio-economic status and language with the goal of conducting future outreach to communities served by Children's Mercy who are underrepresented within the current PFA cohort.



Selected PFAs participate in the mandatory hospital volunteer application process and training program, which includes annual background checks and online training specific to HIPAA, confidentiality, and hospital protocol for codes, safety and hygiene. They also receive individualized, in-person training from the Program Managers to understand the hospital's history, vision and mission, as well as the hospital's engagement opportunities, time commitments and processes. If PFAs join a Council, they receive a PFAC training manual and training on that group's history, purpose, by-laws, meeting location and meeting frequency; PFAC roles and responsibilities; and expectations for PFAC meeting attendance and participation. The PFAC training manual also includes tips for serving on a Council and a volunteer hour- tracking log.

### ***Engaging PFAs through PFACs***

One of the ways PFAs influence Children's Mercy systems of care is by participating in system-wide, departmental or topic-specific PFACs. Children's Mercy has adopted the Health Research & Educational Trust [Framework for Working with Patient and Family Advisors](#), which emphasizes the following key principles: 1) recruiting patients and families with firsthand knowledge; 2) preparing them for their advisory role; 3) ensuring a hospital culture that embraces engagement; 4) implementing improvement initiatives and measures of impact; and 5) sustaining relationships through an ongoing feedback loop that communicates how engagement has led to change and how to be more involved. Children's Mercy implements **three system-wide PFACs**: (1) the Family Advisory Board (FAB); (2) El Consejo de Familias Latinas/Hispanas (the Council of Latino/ Hispanic Families or El Consejo); and (3) the Teen Advisory Board (TAB). These PFACs meet monthly to inform hospital quality, safety and patient experience practices. Each of these three system-wide PFACs are guided by unique by-laws, membership guidelines, patient and family engagement policies, and their own PFAC toolkit or manual. The FAB serves as the



oversight group for the growing number of PFACs at Children's Mercy while the TAB and El Consejo ensure the voice of commonly underrepresented groups are engaged in the hospital advisory process.

The **Family Advisory Board (FAB)** was established in 2003, and all the FAB's 21 family members are primary caregivers of a child who has received care from Children's Mercy. Other members include representation from the PFE Team, hospital administration, medical staff, nursing leadership and psychosocial services. When first established, the FAB only provided guidance on existing projects, but as the model proved to be a viable way for staff to gain knowledge and insight, hospital staff engaged the FAB on projects at all phases, including during initial concept design. FAB guidelines ensure that FAB attendance is comprised of a majority of family participants so the patient and family voice remains strong throughout all topics of conversation. To participate in the FAB, individuals complete the FAB application and are interviewed by the board's Chairperson. FAB members must participate in a minimum of 50% of FAB meetings per year, and when their participation dips below this level, a Program Manager meets with the member to understand the cause of their absence and to assess with the member if a less time-intensive engagement activity (e.g., the PFAC Alumni Program) is more appropriate. There are no term limits for FAB members, and there is a waitlist to join.

The **Teen Advisory Board (TAB)** was established in 1999 to ensure Children's Mercy patients between the ages of 13 and 19 years inform the policy and programs that affect their lives. The TAB, which was the hospital's first PFAC, now has 19 members and has assumed an important role in reviewing patient materials, videos and screening materials to ensure they are appropriate for the adolescent community. Two examples include informing adolescent educational resources about transitioning to adulthood and ensuring appropriate language for suicide screenings. The TAB also worked with hospital staff to make MyCare, Children's Mercy mobile app, more engaging and to pilot and improve robotic technologies that allow patients to access their communities (e.g., the classroom setting) when their medical conditions make it difficult to leave their hospital room or home. The TAB membership is not defined by a specific diagnosis; however, due to the targeted age-range of its members, TAB volunteers do "age out" of membership. TAB participants, like all volunteers, have background checks and HIPAA/confidentiality training as staff and volunteers.

The mission of the Consejo de Familias Latinas/Hispanas is to improve communication and collaboration between families and hospital employees in order to improve medical services.



**El Consejo** was established in 2008 to ensure Spanish-speaking families were included in the advisory process. El Consejo has ten members, five of whom have participated in this Council since its inception.





El Consejo members collaborate with staff to ensure the needs of non-English speaking families are met. Members of Consejo also serve as linkages to the Hispanic community through their participation in community events and health fairs. A well-respected bilingual physician spearheaded the development of this Council, meeting informally with interested families and sharing frequent meals in a safe and trusted space. It became evident this Council would be better served as a separate advisory group with its own norms and processes to allow for a more culturally sensitive interaction among members and hospital leadership. For instance, this Council calls for a more fluid, less rigid meeting agenda and often takes considerably longer to provide critique of practices when compared to other groups, given cultural norms that include hesitancy to question medical expertise. All El Consejo meetings are conducted in Spanish with an interpreter present who uses simultaneous interpretation via headphones for staff members who are not bilingual. El Consejo has raised the awareness for staff about not only language barriers, but also cultural differences and the impact these differences may have on health care.

**Department and topic-specific Patient and Family Advisory Councils (PFACs)** are formal groups of PFAs and staff who meet regularly with a condition-specific scope and purpose. Children's Mercy has 14 of these PFACs, some of which focus on specific hospital departments (e.g., primary care, cardiac care, mental health, neonatal intensive care); specific conditions (e.g., cystic fibrosis, eating disorders, rare conditions, cancer or blood disorders, inflammatory bowel disease, and spinal differences); and important hospital practices (e.g., addressing food allergies and tracheostomies). Each PFAC usually has between eight and 15 participants and policies are in place to ensure PFACs always have more family representatives present during meetings than medical staff. PFACs also range in meeting frequency, with most PFACs meeting monthly and others meeting every other month. The PFACs follow consistent agendas that include updates from hospital staff, planning for upcoming events, and hospital initiatives for which guidance is sought. PFAs who attend meetings receive refreshments or a meal, as well as free parking.

The Patient and Family Engagement Program Managers assume an important role in supporting staff to assess whether a PFAC is warranted (or if another engagement strategy is more appropriate) and to ensure the PFAC is appropriately staffed. **Recruitment** for all Councils typically originate from staff referrals. Families who are referred often have faced obstacles to high-quality care and use the PFAC as an opportunity to assist Children's Mercy to learn from these experiences in order to make improvements. Children's Mercy also has a [website](#) that includes landing pages for each PFAC with a description of the group, meeting guidelines and an electronic application form. Additional outreach and recruitment for PFACs is conducted through clinic-based Patient Family Newsletters and community events. Children's Mercy also ensures that hospital staff are educated on the importance and role of PFAs and PFACs so they can share this information directly with patients and families.

PFAC **agendas** are developed by staff facilitators and the PFAC's Parent Chairs through an interactive process informed by medical staff and community conversations. The PFAC agendas, which are considered working drafts, are then distributed to the entire PFAC one week prior to the meeting to support PFAs' meeting preparation. The PFAC meetings are a combination of **proactive and reactive discussions**. While each PFAC sets its goals for the year and presents its progress during the FAB annual meeting, they also react to hospital issues as they surface. One example of this more reactive approach was when the Spinal Differences PFAC communicated their concern about the lack of surgeon representation within a multi-disciplinary clinic, which led to changes in clinic staffing. The role of PFAs



in **making decisions** as members of the PFAC varies by the project. Often, clinical staff come to PFACs to gather patient and family insights that are then brought back to the department to inform a project. Other times, like in the design of PFAC guidelines, decisions are driven completely by the PFAs themselves. Regardless, the PFACs' decision-making processes are informed by a mutual learning process that encourages transparent problem solving among hospital staff and PFAs.

In addition to the allocation of staff time to co-facilitate and attend PFAC meetings, **additional costs** that are incurred for PFAC implementation include food (approximately \$10.00 per person per meeting) and accommodations, as needed (e.g., childcare, transportation, parking, printing, and video conferencing). PFAC members also are recognized for their contributions in several ways. The annual budget for volunteer gifts, awards and celebratory materials for all PFACs nears \$7,500.00 (averaging less than \$25 per person).

### ***Engaging PFAs in Monitoring and Improving Quality***

Patient and Family Advisors are engaged in numerous quality monitoring and improvement activities. For one, the Children's Mercy Quality and Safety Committee designates one position for a PFA (often a FAB representative) who can bring lived experience and an empathetic viewpoint to the quality and safety discussion. In addition, PFAs have been called upon to provide guidance on standalone quality projects, such as addressing adverse drug events, infections (e.g., those related to catheter and central line use), falls, pressure injuries, sepsis, unplanned extubations, health disparities, readmissions, disclosures, and care transitions. For instance, during one meeting on Adverse Drug Events, a PFA shared a common assumption that the barcode scanning of patient identification bands was to ensure medication payment rather than confirm patients' identities. This resulted in more education for patients and families about the importance of barcode scanning for patient safety.

PFAs also assume a role in the Root Cause Analysis case reviews, hospitals' Lean initiatives, and review and adoption of Clinical Practice Guidelines. They also have joined teams to address Joint Commission Accreditation National Patient Safety Goals for assuring patient identification (Goal #1) and identifying and addressing patient and resident safety risks (Goal #15). Some PFAs also conduct Family Experience Tracers (Tracers). During a Tracer, a PFA accompanies a patient through the entire Children's Mercy visit, observing the staff/family interactions and having in-depth conversations about their experience to help identify unmet needs. While most Tracer activities are conducted by the Program Managers who have direct patient experience, a few PFAs have received extensive training to assume this important role, which has led to improved hospital signage, more accessible family bathrooms, more patient and family-friendly waiting and hospital rooms, and improved discharge planning.

*"I've been in meetings with a room full of doctors and nurses who are all discussing going into a particular direction, and once you have the Program Managers give the parent perspective, you've changed the entire direction of what the group is considering."*

*– Medical Provider*

The resources required for PFA engagement within these quality activities include the staff time required for PFA outreach, communication and training, which is absorbed within the existing quality and safety



staff positions with additional support provided by the PFE Team. Similar to PFACs, there are some costs incurred for PFA meals, parking, childcare and other accommodations. PFA engagement in Tracer activities has been less frequent than other quality activities given the time required for Tracer orientation and training.

### ***Engaging PFAs in Hospital Employee and Trainee Education***

PFAs also serve as partners in patient- and family-centered care education for staff, trainees and the community. The Family as Faculty Program, managed by the Program Managers, allows parents to assume the role of educators, sharing lived experiences to help clinicians improve their patient and family interactions. Through this program, PFAs provide patient- and family- centered care education to new employees at Children's Mercy as a component of employee orientation. PFAs, as Family Educators, host medical residents in their homes to share "a day in the life" of a family with a child with complex medical needs. Family Educators also share their personal stories with residents and graduate nurses by serving on Parent Panels, which include topics that are often sensitive, such as experiencing the death of a child. PFAs who assume the role of a Family Educator receive a small stipend (e.g., \$300 once a year), receive additional training from the Program Managers, and participate in select local, virtual and national seminars, webinars and conferences.

### ***Engaging PFAs in Family Mentoring and Support***

PFAs often engage directly with other parents to provide mentoring and support. For instance, the Parents Offering Parent Support (POPS) is a network of parent volunteers who talk with parents of children who are experiencing traumatic health events to share their own personal experience and provide encouragement. Mentors are recruited by staff recommendation and can apply for this role on the Children's Mercy website. The parent can request a POPS mentor online via the hospital's website and hospital staff also make patient referrals. Parents and mentors connect in-person, via email, phone, and/or text as often as is comfortable for both the parent and the mentor. PFAs also assist in Children's Mercy Family Time, an informal social time where families are supported to step away from caring for their child at bedside to connect directly with other parents. PFAs are encouraged to share their personal experiences and words of advice for their peers during these events which often include meals or snacks. The resources required to implement family mentoring and support include the PFA training to assume a role as mentor, Parent Coordinator support to facilitate matches, and the costs associated with meals and snacks.

### ***Engaging PFAs in Research***

Patients and families are also engaged in Children's Mercy research activities. For one example, PFAs serve as Community Institutional Review Board (IRB) members to ensure research is conducted in a meaningful and empathetic way for patients and consent forms clearly communicate the risks and benefits

*"I have had the pleasure of working with [the Program Managers] on the [online] Allergy Intake Questionnaire. They were a tremendous help providing the researcher with a realistic understanding of what he can expect parents to complete. They also were integral in formatting the questions into language...so parents [are] able to provide useful information."  
– Medical Provider*



for research participants. Currently, there are 36 IRB members of which four are PFAs, but an additional three PFAs may join the IRB soon, leading to 18% of IRB members being PFAs by Spring of 2020. Some PFAs also assume the role of Co-Principal Investigator and as paid research assistants as seen in Patient-Centered Outcomes Research Institute (PCORI) projects. Members of the FAB (current and Alum) and El Consejo assumed a role in PCORI-funded projects exploring the cultural differences in antibiotic use and providing feedback on existing videos intended to combat antibiotic misuse, reporting that they were not adequately engaging and not available in Spanish. This collaboration resulted in a family-friendly Spanish cartoon video appropriate for both parents and children. Resources required to engage patients and families in research includes the dedication of staff time to outreach, communicate with, and train families, as well as funds for paid research assistance roles or engagement stipends, which vary by research project.

## Examples of Impacts and Successes

Children's Mercy patient and family engagement strategies have led to a range of facility improvements, policy changes, and a shift in staff culture, many of which are described below.

- **PFAs have shaped Children's Mercy hospital policies and procedures.** For one, the FAB has been assigned the Reviewer role for many hospital-wide policies, including the Visitation Policy. As a result, the Visitation Policy was modified and renamed (now the Visitation and Welcoming Policy) to recognize that parents are welcomed at any time of day. Also, the Food Allergy PFAC assisted in the creation of the hospital's snack policy, which included the removal of peanuts and the addition of allergy-friendly snacks in all outpatient clinics. This PFAC also worked with hospital staff to maintain the Children's Mercy designation as a national "Center of Excellence" by the Food Allergy and Research Education (FARE). PFAs have informed many other policies including: patient and family engagement; patient- and family-centered care; venipuncture (obtaining intravenous access); visitation; family presence during resuscitation and procedures; financial assistance; and patient rights and responsibilities.

- **PFAs have influenced facility design and improvements.** PFAs informed changes in physical layout, accessibility, and functionality of family bathrooms and the redesign of waiting rooms to be sensitive to family comfort and communication needs.

For instance, PFAs performed physical walkthroughs of planned family bathrooms to point out what was needed for layout and equipment so caregivers could support safe transfers and changing, regardless of patients' age or size. Also due to PFA input, bilingual signage and international symbols were placed throughout the hospital and a separate employee entrance was built to minimize employee shift change disruptions for patients and families entering the hospital. PFAs also are engaged in the architectural design of new sections of the hospital, including the design of a new patient tower and a redesign of the Pediatric Intensive Care Unit (PICU) and the Children's Mercy Research Institute.

*"At Children's, we feel supported and that our voice counts."*

*– Patient Family Advisor*



- **PFAs have enhanced communication.** PFAs have provided guidance on content for patient and family education including a patient welcome video, family activated rapid response video for responding to emergency codes, pre-op bathing video, and sepsis video. PFAs also have provided guidance on written materials, including a family-centered rounds information brochure, a nurse advice line magnet, a sepsis informational brochure, and a “My Child’s Daily Meds” form to educate families on the medications used throughout the family’s stay. PFAs also assisted in the design of communication boards in patients’ rooms to better facilitate communication among the patient, families and care teams.

*Over two years (FY18 and FY19), patient experience data showed a 6.2% increase in Children Mercy’s ability to ease child discomfort after engaging PFAs in identifying strategies to minimize pain associated with needle use.*

- **PFAs have impacted how medical procedures take place.** Tracers, which include Program Managers with patient experience and some PFAs, have uncovered a trend in critiques regarding needle sticks and IV insertion pain. PFAs and staff then collaborated on the “Comfort Promise,” which includes strategies for minimizing pain associated with needle use and reducing stress and anxiety for the patient. Since these changes, patient experience survey data showed a 6.2% increase in “yes, definitely, care providers eased child’s discomfort” over the past two fiscal years (FY18 and FY19).<sup>1</sup> Perioperative services also benefited from engaging PFAs in value stream process mapping to improve how patients move through the same-day surgery corridors, public spaces and patient rooms. In addition to the relocation of the staff entrance, simple, yet meaningful changes have included additional wall outlets for family phone chargers, modifying meal vouchers to include breakfast, and changing the locations where patients say goodbye to their loved ones prior to procedures to decrease stress on families. Since these changes, Perioperative services have experienced reduced waiting room times (10.5 minutes in FY17 to 7.45 minutes in FY19, a decrease of 29%) and improved patient experience (average of 83.2% in FY18 to average of 86.8% in FY19).<sup>2</sup> Other areas where PFAs have influenced patient experience include the development of family-centered rounds (parents and caregivers now join clinicians to discuss their family’s progress and concerns); nurse shift change practices (now at bedside and include the patient and family); and the use of orange wristbands to easily identify the parent/ primary caregivers of admitted patients.

## Engagement Lessons Learned and Solutions

Children’s Mercy’s cultural shift to patient and family engagement has not been without many lessons learned over the years, many of which are described below.

- **Engagement is time consuming and requires dedicated staff time to develop trust.** Children’s Mercy staff have learned that for engagement to work, it requires buy-in and participation from all levels of the organization, as well as from those who you seek to engage. Buy-in does not happen

<sup>1</sup> Children’s Mercy Presentation, Utilizing the Skills and Talents of Our Family Advisors to Improve the Periop Patient & Family Experience (2019).

<sup>2</sup> Ibid.



overnight, and instead happens over time as people develop trust in one another, the process and the outcome. For Children's Mercy, the allocation of dedicated staff who develop and follow predictable patterns of engagement behavior and create environments that encourage self-reflection and co-learning have been key to the development of trust over time. Hospital leaders also have provided clinicians and staff protected time to participate in advisory meetings and interact with patients and families outside of a care-providing setting, which has been essential to the building of trust in the engagement process across hospital operations and clinical departments.

- **Engagement requires clarity in roles, responsibilities, and purpose.** Children's Mercy has learned that the best engagement occurs when everyone is clear on the purpose for engagement and their roles and responsibilities. For example, Children's Mercy medical residents were paired with PFAs as part of a resident problem-solving course. However, PFAs found the residents focused far more on their need for technical knowledge than learning through the patient lens. Those who attend advisory boards or councils can face similar challenges. Hospital staff may not understand why PFAs are present, how to incorporate the feedback provided, or the intended outcomes of the process. Similarly, if PFAs are unclear of their role, which is to represent the broader patient voice, this too can limit progress. Children's Mercy created engagement policies, manuals and templates that support hospital staff and families to understand the purpose of engagement and to gain clarity on their roles. These tools alongside continued training and mentoring by Program Managers has been essential to supporting clarity in purpose and roles.

*"It is difficult work. It takes more time. For instance, our executive interviews took more time because we engaged families in the process. And, sometimes, you get feedback that is very uncomfortable, and the ego balloon is popped. It is easier to just not do it. But, if you are willing to take the feedback, it can set you free as an organization and culture."*

*– Paul Kempinski,  
Children's Mercy  
President & CEO*

- **Engagement requires an emphasis on diversity and inclusion.** Often times, the first phase of engagement focuses on engaging those who are easily reached. While Children's Mercy has created a cultural shift that welcomes patient and family engagement, the next frontier will be ensuring PFAs more consistently reflect underserved communities. Children's Mercy is actively evaluating the demographics of their PFAs against hospital-wide patient and community demographics to inform future targeted PFA outreach strategies. As hospital staff implement new PFA outreach strategies, they will apply lessons learned from El Consejo, including tailoring outreach, engagement and facilitation strategies to the communities targeted.
- **Engagement requires consistent PFA attendance in PFACs and other engagement opportunities.** In most cases, PFACs and other engagement groups vote on the meeting schedule. The majority vote may not suit the work and personal schedules of every PFA member, thus affecting attendance rates. To address this, many PFACs and other engagement groups offer the option to attend meetings by phone or video conference. Transportation and childcare also are obstacles to



attendance for some, so transportation coordination, free parking, valet parking and onsite childcare are provided, as needed.

- **Engagement strategies must grow with the organization.** With 8,000 employees and growing, the intimacy among departments that existed when the organization was smaller is now less common. Growth has led to pockets of impressive engagement alongside engagement practices far less developed. Children's Mercy is working to develop streamlined engagement practices as the hospital grows, touching all administrative and clinical operations throughout the organization. There is some concern among staff that with more standardization comes less flexibility and creativity. Other staff are confident that the engagement culture within Children's Mercy will flourish as the hospital grows.

## Considerations for Replicating and Scaling Work

The experience of Children's Mercy with patient and family engagement highlights key ingredients for successful engagement that should be considered when implementing similar models in other hospital environments.

- **Leadership buy-in.** Children's Mercy has had a steady stream of leaders who value patient and family engagement, who dedicate staffing resources to the cause, and who work tirelessly to steer the ship towards a culture of engagement. Leadership buy-in is essential in creating a culture of humility, which is required to create space for constructive patient and family feedback. Existing leaders have opportunities to engage with PFAs and Program Managers routinely in department and executive meetings to observe the benefits of engagement first-hand. New leaders, prior to being selected, are interviewed by PFAs to understand their engagement philosophy and to inform the hiring selection.
- **Engagement Champions.** Champions can be internal, such as hospital staff and executives, as well as external, such as patients and family advocates. For Children's Mercy, engagement was initiated by a previous Chief Operations Officer, an oncology nurse whose first engagement experience was with cancer survivors. Now, the PFE Team's Program Managers assume a Champion role, bridging hospital staff, patients and families by creating a common language and purpose for all. They ignite the passion for engagement within their colleagues and support their colleagues, as well as patients and families, to develop trust and comfort while participating in engagement activities.
- **Engagement policies, procedures and training.** Patient- and family-centered care and engagement training is provided to all new Children's Mercy employees and is part of continuous education for all clinical staff. PFAs also receive their own individualized training, written training materials, and ongoing mentoring to support their success. Children's Mercy also has found that a thoughtful PFA

*"Patient family engagement starts with organizational culture and leadership."*

*– Paul Kempinski,  
Children's Mercy  
President & CEO*



outreach, recruitment and orientation processes, including standard overview materials, website, application form and engagement manuals allows individuals to examine whether the PFA role is right for them. The PFE Team's Program Managers interview potential PFAs to ensure they understand the time commitment, identify additional mentoring needs, and match the person with the best placement.

- **Facilitation and communication strategies.** Skilled facilitation, including co-facilitating roles for hospital staff and PFAs, supports the engagement of all meeting participants, whether in the room or attending virtually, the ability to move the conversation along, and successful maneuvering of difficult conversations. Children's Mercy also emphasizes the importance of a consistent feedback loop to build trust so those who are engaged understand their input is valued and acted upon, so that they will keep coming back to the engagement table. This feedback loop is ensured through thoughtful and consistent communication strategies: monthly Administrative Update from FAB meetings; monthly emails from PFAC leaders; project-based emails from project teams; ad hoc phone calls with members of the PFE Team; and a designated email address to contact the PFE Team's Program Managers.
- **Engagement incentives.** Knowing you are making a difference was recognized consistently by PFAs as the most important incentive, but refreshments, verbal recognition and recognition with small gifts during holidays and celebratory events or in hospital publications were also appreciated. While Children's Mercy PFAs don't receive stipends for their participation, engagement staff recognize this type of financial incentive may be needed to support engagement of underserved and lower-income communities. Incentives are important not just for PFAs, but also for staff. Hospital staff receive awards (hand-signed cards from leadership, trophies, and meals with the Chief Executive Officer) based on patient experience survey results, patient nominations, and efforts to include patients and families in their work.
- **Dedication of resources.** Children's Mercy PFE Team, the team that oversees the hospital's engagement activities, includes 5.3 FTEs. Staffing-related expenses, excluding benefits, total approximately \$525,000 annually. These staff not only support engagement activities, but also address the strategic goals of the organization (e.g., quality, safety, patient experience, community relations, etc.), which are central to the organization's ability to achieve its mission. The PFE Team also budgets approximately \$600,000 annually for supplies, catering, staff certifications (e.g., Patient Experience Professional certifications), incentives (e.g., trophies, plaques), travel and conferences for the PFE Team and PFAs, and contracted services (e.g., patient experience measurement). While survey processes and provider recognition already exist in many hospital budgets, Children's Mercy has found value in tying these costs directly to their patient and family engagement strategy and budget. Children's Mercy departments own some of the costs for engagement, such as their PFAC food costs (which can be donated by local businesses) and resource allocation for their own department staff participation. Telephonic and video communication tools, which also commonly exist in hospital budgets, also help minimize costs for transportation and other onsite accommodations. While some may find this dedication of resources to be high, Children's Mercy engagement staff emphasize that it is through this investment that they have been able to recruit





PFA's who provide additional hours for events, training and quality assurance that can reduce hospital costs. In 2019 alone, Children's Mercy PFA's invested more than 2,420 hours over 824 separate visits. This estimated allocation includes only hours officially logged, and it does not include an additional 200 or more hours invested by the adolescents who participate in the TAB and hospital activities.