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## Strengthening patient-family engagement amidst a pandemic: Lessons learned and paths forward

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### Abstract

The COVID-19 pandemic was highly disruptive to healthcare and negatively affected healthcare worker and patient experience on multiple levels. Patient Family Advisors serve an important role in partnering with health systems to improve patient experience, yet the work of many volunteer programs were interrupted by the onset of the pandemic, at a time when integrating patient voice into care delivery was sorely needed. This case study presents one health system's experience adapting a system-wide Patient Family Advisory program in the setting of the COVID-19 pandemic, including the transition to a virtual format and increased flexibility in how Patient Family Advisors engage with staff projects. Despite challenges, we were able to maintain meaningful Patient Family Advisory program work throughout the first two years of the pandemic, with at least fifteen Patient Family Advisor project activities each six months. We focused on three primary areas: early patient engagement, increasing visibility of patient engagement, and increasing the effectiveness of our Patient Family Advisors. Adaptation to virtual meetings and adding project-based embedments in addition to traditional council models also allowed the recruitment of new, diverse PFA membership. Commitment to patient engagement and co-design can be challenging but is of particular importance during times of stress for health systems. Flexibility in methods to engage and utilize Patient Family Advisors are needed to maintain success. Increasing agency of Patient Family Advisors will drive meaningful engagement for both volunteers and staff.

### Keywords

Patient engagement, patient experience, COVID-19, health disparities, workforce engagement

### Introduction

A wealth of literature suggests that healthcare delivery is optimized and patient experience is improved when patient voice and perspective are integrated into care design.<sup>1-4</sup> While many strategies may be utilized to solicit patient voice, Patient Family Advisors (PFAs) serve a distinctive volunteer role as fully focused on improving patient experience, with a high level of engagement and commitment.<sup>3, 5, 6</sup> Rather than a singular patient speaking to their own particular experience, PFAs approach their role with a mindset of speaking on behalf of all patients, and are uniquely prepared to participate in co-design, often in a council setting of other like-minded patient experience advocates.

The last few years have brought multiple disruptions to healthcare, with significant impacts on patients and healthcare workers alike. Not only did the COVID-19 pandemic place extraordinary stress on individuals and health systems through the world, the United States has also seen a notable period of civic and political unrest, increased recognition of health inequities,<sup>7</sup> and a sharp rise in medical misinformation.<sup>8</sup> The combination of these

factors has been associated with a growing distrust of healthcare systems,<sup>9</sup> healthcare worker staffing shortages, and increased violence and disruptive behaviors in hospitals and clinics.<sup>10, 11</sup> Not surprisingly, patient experience and physical and mental wellbeing often suffered as a result, with increases noted in metrics such as patient falls, depressive symptoms, aggression, and overall dissatisfaction.<sup>12-18</sup>

Unfortunately, the rapid onset COVID-19 pandemic in early 2020 demanded social distancing to limit virus spread and limited entry of visitors into healthcare facilities, which also negatively affected patient experience.<sup>16, 17, 19</sup> Most health care systems also immediately put their volunteer programs on hiatus to protect patients, staff, and volunteers alike. PFAs were typically included in this cessation of volunteer activities, leaving healthcare organizations bereft of patient voice at a time when it was sorely needed to help address new challenges. This narrative report will describe our experience maintaining and adapting our PFA program over the first two years of the pandemic, using a three-pronged approach: engaging patient voice early, building PFA effectiveness, and increasing PFA visibility.

## The Duke Patient Family Advisory Program

The Duke PFA program was initiated in 2005 with a single health system patient family advisory council (PFAC) of 8 members, modeled on the Dana Farber PFA model.<sup>20</sup> This system-wide council initially served as a patient voice ‘sounding board’ for initiatives and projects. Around 2010, a concerted effort was made to move this work closer to the point of care, with development of individual PFA councils that were directly tied to a specific specialty, clinical service line, or individual entity within the health system. A Children’s PFAC was added in 2011, followed by an Oncology PFAC in 2013. By 2019, the Duke PFA Program consisted of 13 individual councils with over 80 volunteers, representing over 1200 volunteer hours per year. PFA projects were varied, and included examples of feedback on patient education materials; electronic health record interface; wayfinding, accessibility, and signage; after visit summary redesign; physical design of new spaces; and emotional journey mapping.

General council structure and characteristics are described in Table 1. Councils are led jointly by one health system staff member and one PFA volunteer, to model the partnership which is the aim of these councils. Formation of a new council requires a firm commitment from local leadership as well as an identified staff co-chair. Volunteer recruitment occurs through multiple paths, including flyers posted throughout the hospitals and clinics, health system website, emails through our electronic patient portal, and direct recruitment from staff and other volunteers. When a volunteer expresses interest in becoming a PFA, they are initially screened by our PFA program coordinator for suitability, and they meet with an existing PFAC. Screening includes background check and a screen for active litigation, as well as a conversation with the volunteer about their motivation to be a PFA, including objectivity, collaborative nature, and focus beyond a single issue. Volunteers then participate in a brief orientation and are paired with a council which aligns with their interests and based on that individual council’s needs. More recently, we have recruited some PFAs who are not affiliated with any

specific council, but rather join in project-based work and focus groups as needed. Attention is also paid to recruitment of diverse PFAs who can represent our patient population.

Our PFACs coexist with two other programs which help solicit patient voice. The first is a digital customer feedback platform which is primarily driven by surveys to targeted patient populations who have expressed willingness to participate in feedback.<sup>21</sup> The second is a community based, clinical research platform which has a deeper pool of underrepresented patients, and is primarily utilized for targeted focus groups or in-depth feedback for research protocols and special projects.

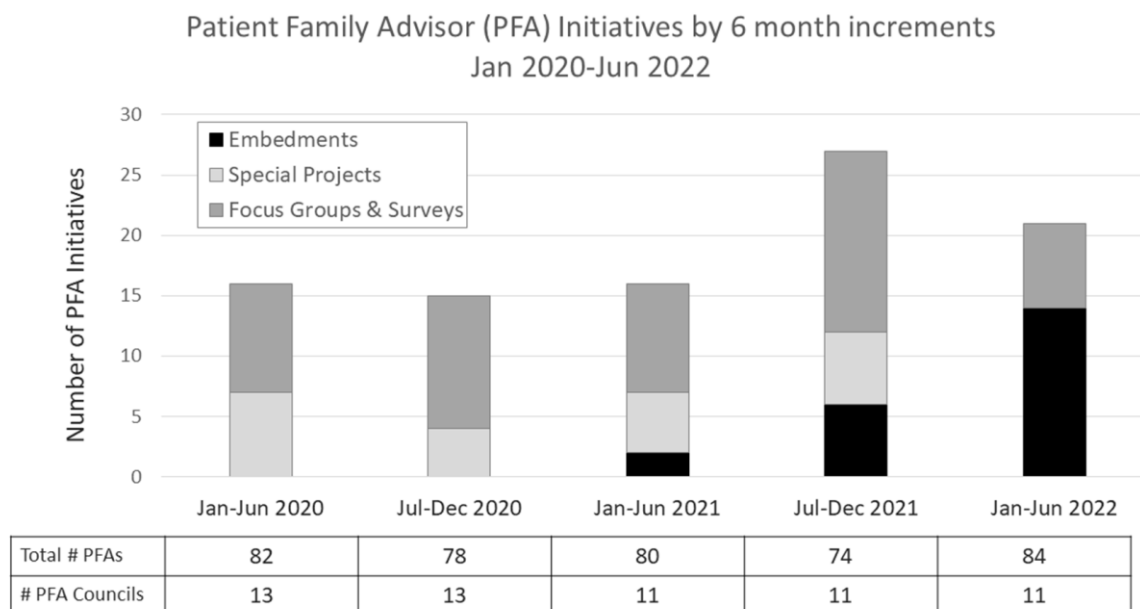
## Adapting to the Pandemic

Like many other health systems, visitation restrictions forced by the COVID-19 pandemic led to a sudden cessation to all in-person volunteer activities in March of 2020. Yet our PFAs very much wished to continue their work and partnership, and many councils rapidly transitioned to virtual meetings via Zoom or WebEx platforms. Using these new platforms, our PFAs were the only volunteers at our health system to continue their work uninterrupted despite the new restrictions; in fact, they were the only active volunteer group for the first two years of the pandemic. At the same time, much of the in-hospital committee work was transitioning to the same digital platforms, which would ultimately allow a different engagement of PFAs in committee and project work.

Figure 1 shows a tally of the ongoing work from the onset of the pandemic onward. With recognition that staff experience and patient experience are inexorably linked, examples of projects early in the pandemic included support of hospital and clinic staff, including creation of wellness packets for staff and solicitation of donations for a newly-created food pantry for employees facing food

**Table 1. Guiding Principles for Structure of the Duke Patient Family Advisory Councils**

- Each council has 2 co-chairs: a volunteer co-chair and a staff co-chair
- Each council aims to have more volunteer PFA members than staff representatives
- Each council has governance documents dictating membership expectations, term limits, etc.
- PFAs are screened for suitability and then oriented to the expectations of being a PFA
- New PFAs are interviewed by the existing council leadership for a potential invite to join the council, focusing on overall fit and council needs.

**Figure 1. Patient Family Advisor Program Membership & Initiatives Over the First Two Years of the Pandemic**

insecurity. Focus quickly turned back to patient experience and increasing visibility of the PFA program, with examples of projects including multiple PFAs recording their own stories to educate staff about patient experience, participation in redesign of several patient visitor guides, delivering water to visitors waiting for hospital entry amidst visitation restrictions, review of patient education materials, expansion of behavioral health consultation across inpatient services, and engagement with a project on family presence during resuscitation. Other projects were more community focused, including PFAs staffing non-clinical roles in our community based COVID vaccination sites and information sessions, particularly in underserved communities. Finally, the PFA program made a concerted push to directly embed PFAs in project work as committee or taskforce members, described in further detail below.

To add to the challenge of the pandemic, the murder of George Floyd in May of 2020 (along with several other high profile tragedies) highlighted systemic inequities in a new way. The subsequent focus on health equity, along with clear data showing disparate COVID outcomes for historically marginalized patient populations, emphasized the need to integrate the voice of these vulnerable populations into health care design. The PFA program became a valued avenue to access the historically marginalized patient voice, and helped make connections between clinicians seeking this and representative PFAs, community leaders, and minority advocacy groups such as LATIN-19.<sup>22</sup> Our adaptations to virtual platforms were

fortuitous for this effort, as these platforms in addition to the flexibility to serve as a PFA without being tied to a specific council allowed us to recruit and engage individuals who would have previously not been able to serve due to timing and frequency of council meetings.

Despite the successes of some of our PFACs, the ongoing challenges of the pandemic left some administrative leaders so overwhelmed or distracted with other priorities that it was no longer feasible for them to give the appropriate attention and time needed to maintain a functional PFAC. For these areas, the choice was offered to pivot from the traditional council model to a model where individual PFAs could participate in ongoing projects, but with no scheduled PFAC meetings.

### Increasing Patient Family Advisor Effectiveness

In an effort to be proactive in bringing patient voice earlier to initiatives, the Duke PFA program has actively sought to embed PFAs as members of task forces and committees. This concept helps move PFACs from providing feedback on nearly complete projects to being more actively engaged on the co-design of these initiatives, hopefully resulting in more patient and family centered project results. While this impetus had begun prior to the pandemic, we did see a rapid escalation of progress on embedment since that time (Figure 1).

With disruption of many ongoing projects at the pandemic's onset, our PFA program leadership used that

gap in PFA work to better prepare our PFAs to be embedded alongside staff. In the months leading up to the pandemic, our health system was in the midst of training employees in Lean methodology and culture, including A3 quality improvement problem solving.<sup>23-25</sup> We therefore offered to train select PFAs in this same A3 problem solving method so that they would be better prepared to be impactful members during project embedments. Over a period of five virtual teaching sessions, nine PFAs were trained in this methodology. Following an introductory session, each of the next four sessions focused on one quadrant of the A3 diagram: current condition and defining the problem to be solved; understanding the current condition; envisioning the target condition; and selecting a test of change with appropriate metrics. We received positive feedback that obtaining these skills increased the PFAs’ agency in problem solving and working with staff, and we are moving forward with training of additional PFAs in A3 methodology.

Examples of recent embedments of PFAs on workgroups include a redesign of the pediatric tracheostomy pathway, a patient rounding taskforce, development of a screening process for social drivers of health upon hospital admission, and management of pain and opioid use in the emergency department. We have not yet crossed all the hurdles to include PFAs on peer-protected committees, but we have two PFAs embedded on the Chancellor’s Quality Improvement Executive Committee in addition to multiple other committees throughout the health system.

### Discussion and Lessons Learned

This narrative report of how the Duke PFA Program adapted to the pandemic to maintain and strengthen patient engagement demonstrates the importance being flexible to support patient engagement. While many of the

changes described here were forced upon us by the pandemic, there were some adjustments which promise to have notable advantages in the future. Key lessons are summarized in Table 2.

While a majority of health systems’ PFACs did go on hiatus during the early stages of the pandemic, there were other centers that made a similar shift to ours in terms of virtual PFA engagement.<sup>26-28</sup> The forced transition to virtual engagement had a few unintended benefits. The increased use of virtual meetings and virtual work allowed accessibility of PFA opportunities to a group of volunteers who previously struggled to make council meetings, either due to time commitment or ability to travel.<sup>26</sup> Similarly, the restriction on in-person activity and the increased capacity for virtual platforms allowed us to dramatically simplify the PFA onboarding process, reducing the need for travel for volunteer screening and in-person orientation, and ultimately making the process more tenable for volunteers. Each of these changes directly benefitted those PFAs with limited resources, allowing for the potential to recruit more diverse PFA representation. Lack of representative diversity is a common challenge for PFACs, and the ability to recruit more diverse PFAs using virtual platforms was also highlighted in a multicenter study of children’s hospital PFACs during the pandemic.<sup>29</sup>

Much of the literature on patient experience during the pandemic was focused on the transition of patient visits to virtual telehealth platforms, with generally high satisfaction and reasonable concordance in disease management.<sup>30-37</sup> It follows that similar strategies might be adapted to engage PFAs to improve patient experience. Unfortunately, the shift to virtual engagement was not always a positive experience for PFA volunteers.<sup>27</sup> Not only were there the technical issues including lack of comfort with virtual platforms and access to internet, but published literature

**Table 2. Insights and Lessons Learned**

Lesson Learned	Commentary
Virtual options allow participation by a more diverse Patient Family Advisor population	Virtual options remove time and cost of travel and allow greater flexibility. However, some Patient Family Advisors may not have access to or comfort with the necessary technology, and there is the potential for more passive engagement.
Consider offering training opportunities for Patient Family Advisors	Personal development provides the dual benefit of preparing Patient Family Advisors to be active partners in improvement activities, as well as perceived individual value to participation as volunteers.
Engage Patient Family Advisors in community-based activities	Community activities may not be subject to the same visitation limitations as healthcare facilities, yet are meaningful interactions for Patient Family Advisors and strengthen community bonds for the health system.
Build flexibility into Patient Family Advisor engagement opportunities	Moving beyond a strict council model to allow direct embedment of Patient Family Advisors in workgroups, projects, and committees results in earlier integration of patient voice and a more direct partnership between staff and volunteers.



tells us that some PFAs found virtual meetings to be a more passive, superficial engagement.<sup>27</sup> Passive engagement is a real risk of virtual meetings, and can be combatted with bidirectional engagement rather than seeking unidirectional feedback. We witnessed some turnover in our PFAs during the first few years of the pandemic but were fortunately able to recruit other volunteers to maintain the overall numbers in the program. Two strategies that were particularly well received by our PFAs were the opportunity to build their own skillset through training and the subsequent ability to directly embed with staff on projects, rather than sitting in a silo to provide only intermittent feedback.

Engaging PFAs in community-based activities had multiple benefits as well. Participating in pop-up COVID vaccine sites were incredibly meaningful for our PFAs and freed up clinical staff to remain in the hospital and clinics. Use of PFAs in these sites and other COVID events also fostered a connection to our historically marginalized communities, which was of particular importance given a sharp increase in medical misinformation and distrust occurring during the pandemic. We expect that community partnerships will allow our PFAs to grow in their roles as ambassadors for our health system, and open additional pathways to solicit previously silent patient voices.

Another key lesson learned was to meet leaders where they are. When faced with the new and overwhelming demands of the pandemic, not all of our leaders had the bandwidth to continue to support PFACs in manner that was necessary to make the volunteer experience meaningful. The hard decision to put two of our councils on indefinite hiatus was well received by both the administrators who were stretched in their time commitments as well as the volunteers, who felt underutilized in a council that was not progressing and who were interested in other ways to contribute. To maintain the patient engagement in these areas, we continue to work with local leaders to identify embedment and individual project opportunities for PFAs to contribute outside of the traditional council structure.

As we continue to adjust to what healthcare will look like in the future, patient co-design will develop systems that are more accessible, equitable, and safer - all of which will lead to improved results for patients and staff alike. Our goal is to have health system leaders asking of any initiative: ‘... and how did you include patient voice in this project?’ PFAs can be valuable partners in that work, and healthcare systems must be adaptable to meet the heterogeneous needs and expectations of these volunteers. Aligning PFA work with system priorities and embedding PFAs early in project work are strategies that are mutually beneficially to the volunteer experience and the project outcome.

## Conclusion

The COVID-19 pandemic brought new challenges to Patient Family Advisory programs which necessitated the development of novel strategies to maintain strong patient engagement. Creative use of virtual platforms allow work to continue and open new avenues for recruitment of diverse volunteers. Focusing volunteer work on project and committee work in addition to advisory councils allows for meaningful engagement and can be assisted by giving volunteers the tools to contribute in an effective manner.

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