

# RAISE YOUR VOICE

Patients & Caregivers Effecting Change



2023 Post-Symposium Debrief & Analysis



Memorial Sloan Kettering  
Cancer Center

**PFACQ**

## A Note from the Raise Your Voice Symposium Directors

In September, 2023, we hosted the inaugural Raise Your Voice symposium as a way for representatives of leading cancer centers around the country to come together to discuss how best to leverage patient and family advisory councils to advance patient-centered care. It was a spirited and energizing three days for this important community. We developed this Debrief and Analysis—a comprehensive summary of the insights of all sessions, as well as links to important resources such as all speaker presentations, and an analysis of the valuable feedback provided by attendees. While designed to be a useful tool in helping attendees synthesize their experience and act on what they learned, we also feel it can be used by anyone looking to improve how patient and family advisory councils perform. Finally, it offers a sense of what to expect for those joining us at the 2025 Raise Your Voice symposium, scheduled to take place from October 7 -9, 2025.



We feel this document is reflective of the spirit of the symposium and clearly lays out the value in attending. We look forward to continuing to strengthen our relationship with one another—and hope to see you all back in New York!

Kind Regards,

Frank Licciardi  
Chair Emeritus, PFACQ  
Memorial Sloan Kettering Cancer Center

Johanna Schoen  
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## Overview

From September 13 – 15, 2023, Memorial Sloan Kettering’s (MSK) Patient & Family Advisory Council for Quality (PFACQ) hosted its inaugural Raise Your Voice symposium—bringing together patients, care partners, and hospital staff focused on how to better partner with one another to advance patient-centered care.

### Key Resources

Raise Your Voice Program. The program provides the full context of the 2023 symposium, as well as the schedule and speaker biographies.

[Click here to access.](#)

Raise Your Voice Syllabus. The syllabus provides access to all presentations.

[Click here to access.](#)

## Session Debrief

The Raise Your Voice symposium began with a “soft open” on Wednesday afternoon at which Frank Licciardi spoke to the importance of open dialogue around grief and end-of-life preparedness and detailed how PFACQ brought the international phenomenon known as Death Over Dinner to Memorial Sloan Kettering (MSK) in the hope of eliminating the taboo around death and dying. The presentation was followed by having all attendees participate firsthand in a spirited instance of Death Over Dinner.

The Death Over Dinner experience brought a palpable energy to the symposium and facilitated the establishment of profound connections among attendees. Many in attendance inquired about bringing the initiative to their respective hospitals. While it represents a significant undertaking, it is a unique way for PFACs to impact the cultural DNA of an organization.

On Thursday morning, Johanna Schoen welcomed everyone with a few words about our motivation for the symposium before handing it off to MSK’s Physician-in-Chief, Lisa DeAngelis, who spoke to the importance of MSK’s PFACQ and to the ways in which patients and clinicians are in a special partnership with one another along the cancer journey.



## Session Debrief (continued)

Barron Lerner’s keynote took us back to the often-forgotten history of patient activism in cancer care. His insightful presentation illustrated the maturation of activism—from the groundbreaking efforts of Terese Lasser who established Reach for Recovery to patients protesting radical mastectomies. As one audience member noted afterwards, the effectiveness of breast cancer activism—and later patient activism in the HIV/AIDS community—came from the anger that women (and subsequently gay men and their allies) felt over the ways in which they were treated by their respective health care providers. Once patients demanded that treatment options be based on clinical studies and evidence, patients and clinicians were finally able to establish trust-based partnerships which signaled the start of the critical transition for activism from outside the hospital to activism on the inside. Barron also reminded us of the importance of remaining humble and considering the context as we might evaluate today’s treatment protocols differently 30 years from now.



Fernanda Polubriaginof moderated a fascinating discussion with Deborah Estrin about the role of digital technology along the cancer journey. Deborah spoke to the value of capturing the digital traces we already generate—what she referred to as “small data”—and turning them into actionable insights for patients and clinicians to make optimal health choices. For example, she spoke of the introduction of wearables and the breadth of information they collect—offering a truer sense of a patient’s day (e.g., when they leave the house, how far they go, how long they are gone, etc.). She also spoke of novel uses of these technologies such as leveraging the touch screen of an Apple watch for a Parkinson’s tap test. Given the ability to leverage these novel technologies, she spoke to the promise of more precision-based treatments but also noted the challenges that these technologies bring—such as the need to engage patients and care partners who may be uncomfortable with emerging technologies. Deborah also voiced skepticism regarding AI in medicine. As she noted, there are more constraints in medicine—it is not acceptable to move so quickly that things break. Decisions must be explained and interrogated—something that is not in the nature of generative AI tools. Furthermore, AI requires experts be able to detect AI’s inaccuracies—known euphemistically as “hallucinations.”



We started the afternoon with a panel hosted by Kate Niehaus of MSK’s PFACQ which focused on the recruitment and onboarding functions of patient and family advisory



## Session Debrief (continued)

councils. While we heard varying creative approaches, all PFACs seem to be facing challenges in attracting volunteers who represent the full breadth of diversity of cancer patients.

Jessica MacIntyre (Sylvester Comprehensive Cancer Center) spoke to the importance of leveraging their Co-Chairs during the interview

process and highlighted how they utilize their Office of Patient Experience for onboarding. She then spoke of a robust gap analysis exercise undertaken to improve diversity—and the key role of the Community Advisory Council (CAC) in informing and providing support bi-directionally for PFAC interviews, grounding the work of PFAC, and offering the ability to offer resources as needed. Jessica also spoke of the introduction of the PFAC “Seal of Approval”—and showed an example of its placement on an educational piece of content (“Suggested Questions to Ask Hospice Agencies.”) Tate Rondot (Siteman Cancer Center) spoke of a robust assessment undertaken by Siteman’s PFAC to understand everything from demographic gaps to the interests and priorities of current members. Tate is hopeful that the development of a new marketing plan will both increase the impact across Siteman and—given their diverse catchment area—facilitate the recruitment of new members from underrepresented groups. Jacklyn Le (MD Anderson Cancer Center), spoke to their Patient and Family Advisor Program’s (PFAP) journey transforming recruitment and onboarding opportunities into best practices. Such best practices included: having advisors (and not employees) select advisors; leveraging MyChart to announce PFAP recruitment windows; and the development of a PFAP Steering committee, comprising 13 members, who would manage mission-critical tasks such as interviewing and scoring candidates, deal with cases in which a member’s term does not get renewed, and vet new initiatives.



Eliza Weber of MSK’s PFACQ hosted a panel that showcased how PFACs leveraged their seat at the table. Keren Stronach (UCSF) spoke to how UCSF’s PFAC engages patients for a better patient experience. Keren introduced us to UCSF’s process of leveraging patient interviews to uncover invisible errors—such as low-income patients paying high transportation fees that could be covered by insurance. Keren also illustrated how to make use of stories to illustrate problems—such as the patient struggling throughout the night in the ER, only to ultimately have a five-minute procedure to clear her feeding tube. In addition, Keren reminded us to ask questions that PressGaney may not ask



## Session Debrief (continued)

given the changing model of healthcare delivery—and to be mindful of patients' situations as we seek answers (e.g., not using MyChart to ask patients with housing and food insecurities about their housing and food insecurities). Margaret Brennan (Sidney Kimmel Comprehensive Cancer Center / Johns Hopkins), reminded us to secure buy-in of those affected by change—and that doing so



depended on the balance between the perceived burden imposed by the change versus the perceived benefit the change will bring. She cautioned that before we push that proverbial first domino, we need to be cognizant that what we may think are small changes may have larger implications down the road. Cristina Perez and David Dauman (Moffitt Cancer Center) spoke of their PFAC's successes in gaining recognition from the highest levels at the institution—buoyed by their direct reporting structure to Moffitt's COO and the presence of 18 Moffitt leaders on PFAC, including the COO, CMO, CNO, VP of Ambulatory and Virtual Care, VP of Facilities and Support and the VP of Medical Group. Their PFAC touches just about every facet of the organization, so it was no surprise to hear of their impact on rising patient experience scores. David spoke to the value proposition model and noted key lessons, including having a clear mission, carefully selecting patients and care partners, identifying key causes, how to push passion projects and share wins, and knowing when to let go. We also heard of creative and rewarding initiatives, such as bringing patients enrolled in clinical trials into the lab to connect them with researchers.

In the final presentation of the day, Meg DeWitt (Memorial Sloan Kettering) offered a thought-provoking presentation on the implications of recent trends in health care for the work PFACs do. She started by offering a primer on the Competitive Intelligence function—including offering attendees ways that they may learn what to monitor, how to monitor, and how to transform information into insights. Meg then masterfully walked us through six major trends:



expanding cancer facilities and services; increasing patient steerage; changing decision-drivers among patients and care partners; changing care delivery models; broadening of cancer services; and increasing focus on health equity. For each trend, she discussed the evidence (including detailed sources) and the implications and asked attendees to discuss the “so what” of each trend. Among the more impactful trends from a patient advocacy perspective is the expansion of cancer facilities and the subsequent pressure on health systems to direct patients to, and keep them in, their facilities for care. Payors, like insurers and employers, are also trying to direct patients to the highest “value”



## Session Debrief (continued)

provider. These recommendations and referrals may not be in patients' best interests—cancer patients may be presented with fewer options, or subtly steered based on the incentives of other stakeholders. Another particularly impactful, and troubling, trend was the increasing loss of trust in experts, further contributing to decision-making about clinical care based on factors other than seeking “the best.” The final trend, increasing focus on health equity, has a particularly impactful “so what” for PFACs—as the focus on promoting equitable care naturally points to the need to consider health equity when recruiting new PFAC members. How can we meet the needs of the increased diversity among cancer patients?

On Friday morning, attendees had the opportunity to join a networking breakfast alongside many of MSK's leaders—all who have played a role in PFACQ's success. Following this session, MSK's Operational Excellence team—Ann Thaler-Shore, Erika Duggan, Alison Nalezynski, and Monica Styles—walked attendees through the value of systematic problem solving, specifically A3 Thinking, as an ideal problem-solving approach—in particular, if the problem and cause are unknown and the solution requires systems thinking. Attendees designed a problem statement around end-of-life care for their respective organizations, leading to a longer discussion about the ways that our respective institutions deal with questions of end-of-life conversations. We are hopeful that attendees walked away with an appreciation for this systemic approach which may not always be intuitive within the context of volunteer-driven initiatives. We encourage all PFACs to explore a partnership with their hospital's version of Operational Excellence!

Ray Gustin (Co-Chair of MSK's PFACQ) hosted the final panel of the symposium focused on overcoming challenges and effecting change. Donald Levine from the University of Chicago Cancer Center gave a moving account of his late wife's words to doctors about the importance of compassion, communication,



## Session Debrief (continued)

and touch—physical and emotional—and shared his hard-learned lessons for care partners, including: urging care partners to care for themselves; to accompany patients to as many doctor appointments as possible; to bring questions and concerns with them; to understand the medications being given; to be present when home health care people provide care; to understand that they will bear the brunt of a patient’s frustrations; to be prepared that at some point they may be asked to hasten the process; to try to have someone they can talk with; and to be sure that once their role as care partner has ended, they avail themselves of counseling services. Jenny Dahlstein (Dana-Farber Cancer Institute), focused her presentation on telling one’s story as a PFAC advocate. Jenny walked through the PFAC advocacy curriculum, including training volunteers on recognizing and managing unconscious bias; listening and speaking with candor; having courageous conversations; telling your story as an advocate; cross-cultural communication; and being a patient/family research partner. Of particular note was Jenny explaining the value of DFCI’s Speakers Bureau—it offers peer-to-peer support; helps members develop and write their cancer experience story (including how to draw attention to particular messages); and practice story-sharing while receiving supportive feedback from fellow council members. Monica Cfarku (Duke Cancer Institute) then presented about the reimagining of the bell at Duke. She spoke to the controversies surrounding the ringing of the bell. While some in the community fully supported having patients ring the bell upon completing treatment, others were concerned about the proximity of the bell (located just outside treatment rooms) to others—and whether it was audible to those patients and families who might never have the opportunity to ring the bell. After much deliberation, the decision was made to place the bell outside of the hospital building on the Duke grounds. Installed on the 50th anniversary of the Duke Cancer Institute, the new location now allows anyone within the Duke community to ring the bell for any reason. Monica spoke to how often the beautiful sounds of the bell can be heard—it is referred to as the “sound of hope,” which are the words inscribed on the plaque at the base of the bell / art installation, along with the words “Ring the bell to spread hope to the Duke Cancer community.”





## Session Debrief (continued)

To conclude the symposium, Javi Arenas and Kim Burgas, Design Strategists within MSK's Strategy & Innovation team, led an interactive workshop on visualizing the patient journey. As context to their work, Javi and Kim defined human-centered design, an approach for solving complex problems and envisioning new possibilities that center the needs of human beings. This discipline is particularly germane to our work as patient and care partner advocates given that it relies on listening and understanding human (more specifically, in our case, patients' and care partners') needs. They then discussed one of our joint projects in which we hope to visualize the patient journey to help clinicians communicate with patients and to help patients and care partners orient themselves and their cancer experience. As part of the discovery phase of this project, Kim and Javi interviewed MSK clinicians about key challenges associated with end-of-life dialogue. They shared a series of quotes collected as part of these interviews. We then broke into groups for an activity in which we used one of the quotes as inspiration to build a concept for expectation-setting conversations. During the final moments of the symposium, each group delivered a report-out of their respective concepts which led to inspiring discussion among attendees. One highlight came from Chloe Shevlin of Smilow Cancer Hospital (Yale) who spoke of NEST (non-elective solid tumor treatment verification process)—a novel process created in response to a serious safety event where they identified the need for a standard process to evaluate the risks and benefits of inpatient chemo administration.

And with that, the experience known as the Raise Your Voice symposium came to a close!



## Survey Analysis

Attendees were given a survey to assess the degree to which they liked each session. Below is the compiled analysis of the responses.

Session:	Strongly Like	Somewhat Like	Neutral	Somewhat Dislike	Strongly Dislike
Death Over Dinner: Inspiring Conversations About Life and Death	100%	0%	0%	0%	0%
Welcome and Opening Remarks	86%	14%	0%	0%	0%
The Often-Forgotten History of Breast Cancer Activism	93%	7%	0%	0%	0%
Digital Technology in the Cancer Journey	67%	19%	11%	4%	0%
Panel: Recruitment and Onboarding of Patient and Caregiver Advisors	93%	7%	0%	0%	0%
Panel: Leveraging Your Seat at the Table	93%	7%	0%	0%	0%
Major Trends Shaping Healthcare Delivery	79%	21%	0%	0%	0%
Networking Breakfast: Getting to Know the Leaders of MSK	78%	13%	9%	0%	0%
Systematic Problem Solving to Foster Patient-Centric Continuous Improvement	77%	13%	10%	0%	0%
Panel: Overcoming Challenges and Effecting Change	93%	3%	3%	0%	0%
Visualizing the Patient Journey Workshop	73%	19%	8%	0%	0%



## Survey Analysis (continued)

Attendees were also encouraged to share open-form feedback about sessions and we are including a representative sampling of these comments below.

Would you like to share any feedback about the overall symposium?



*Thank you for a tremendously enjoyable, inspiring, and enlightening few days, all done in a safe/trusting culture. The spectrum from tangible takeaways, customizable tools to thought provoking dialogue was well balanced. The positive energy and care in that room was palpable. Groundbreaking work here, thank you from the bottom of my heart!*

*Expertly organized and executed. Wonderful hospitality from everyone from MSK. I loved building relationships from people all over the country.*



*I think this symposium was absolutely wonderful. The most impactful conference I have ever attended. I would love to be a part of the next one!*

*I was blown away by this symposium. For the first of its kind, it set the bar extremely high. Inspiring and impactful are two words that come to mind. I feel very grateful and lucky that I was able to attend.*



*Inspiring couple of days and great to hear from other Cancer orgs across the country. Frank and Johanna's work is inspirational and their ability to captivate an audience is enviable.*

*Incredibly executed. Reflective and healing. Thank you!*



*This was such an impactful event that built strong relationships that only grew in strength throughout the conference;*

*I learned so much and feel energized about my role in PFAC.*







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