Lived Experience Matters: Patient Engagement Improves Cancer Care, Research

Nearly 15 years in, Fred Hutch Patient and Family Engagement Program continues to inform care as it expands to match advocates with researchers.

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Some patients become advocates because everything went right: the diagnosis was made early, the surgery went well, the cancer-driving mutation was found and communicated to other family members, giving them a leg-up on prevention.

Others get involved because something went very, very wrong.

Such was the case for Brandelyn Bergstedt, director of Fred Hutch Cancer Center's Patient Experience Program, whose personal experience with a misdiagnosis while pregnant forged a path into patient advocacy.

"I got into health care because I experienced a medical error during pre-term labor," said Bergstedt, whose extremely premature daughter (now 21) nearly died due to the flawed advice. After requesting a transfer to UW Medical Center – Montlake and giving birth at 24 weeks, Bergstedt got involved as a volunteer UW Medicine patient advisor, which she said, "taught me the difference a patient's voice could make."

Patients and caregivers going through cancer could provide equally valuable insights, Bergstedt believed, so in 2011, she came to Fred Hutch to start the Patient and Family Engagement Program, or PFE. Today, PFE is one part of Patient Experience, which is dedicated to centering patient needs.

What's patient engagement?

Making sure patient and family perspectives are heard and incorporated into clinical care at Fred Hutch is the program's main mission.

And since its launch, hundreds of advisors/advocates have volunteered their time and expertise on committees, focus groups, storytelling panels and at events, providing crucial insights regarding the patient experience and how it can be improved.

Now the program has expanded and is actively matching patient advocates with Fred Hutch clinical researchers and public health scientists to help them design more authentic and participant-friendly clinical trials and cancer prevention studies.

Granting organizations often require patient buy-in and active collaboration such as providing letters of support, tweaking grant proposals to improve access and helping to disseminate findings after they're published. A stable of advocates can be an advantage in an increasingly competitive funding environment.

Patient advisors are also helpful when it comes to administrative, logistical and pragmatic concerns.

"It's been really wonderful to show patients and caregivers the value they bring," said Erin Burke, program manager for PFE. "When we designed our second clinic building, patients were very much involved, sharing perspectives on the waiting rooms and the space and patient needs. We wanted them to be a part of that from the beginning."

But the program is not looking for pats on the back from these patients. Bergstedt said they actively seek constructive criticism.

"Patient Engagement is not the department you go to with a specific complaint about care — that's Patient Relations," Bergstedt said. "But it's also not a 'yes program.' We need to know what we can do better, how we can improve. I rely on the engagement program to be an early alarm system for us. Staff and providers may not be privy to things patients experience unless they speak up — and some patients don't."

Patient advocates can participate in multiple ways, Burke and Bergstedt said. The program is best known for its Patient and Family Advisory Council, or PFAC, which currently boasts 14 members, who serve alongside staff and executive leaders and meet once a month.

"But the PFE program is not just the council," Bergstedt stressed. "We also have other patients who partner on all kinds of things. We have over 90 active advisors and more than 600 e-patient advisors."

These advisors are often tapped to respond to quick questions, surveys and calls for patient involvement and have been known to point out cracks in clinical communications. A year ago, for instance, patient advisors were asked to identify areas where they saw care gaps.

"One of those areas was 'care beyond treatment,'" Burke said. "Half of our advisors didn't know that there was a program called Survivorship offering that."

Other areas they flagged as needing more attention: holistic care; patient-centered education and empowerment; practical support (think transportation and other amenities); equitable access to research and financial support and guidance.

Giving back – and giving feedback

Anisa Ishida of Seattle, a 46-year-old director of marketing diagnosed with lobular breast cancer eight years ago, is a member of both the PFAC and the larger advisor group. She also serves on Fred Hutch's Quality Oversight Committee. (All of Fred Hutch's quality committees include patient and caregiver advisors as voting members.)

Why did she get involved?

"I've always participated in anything Fred Hutch," she said. "I really am a mascot for them. The trajectory of my care really changed once I got there."

While some patients are hesitant to return to the place where they were diagnosed and/or treated, Ishida said Fred Hutch feels "like a comforting place."

"A lot of people feel anxiety wherever they had treatment, but for me, it's the opposite," she said. "Giving feedback as a patient definitely appealed to me."

From the very first project, which involved making sure there was sufficient signage for patients unfamiliar with the South Lake Union clinic location— recently renamed the Fred Hutch Sloan Clinic — Ishida said she was impressed.

"I didn't expect to have this much of an impact," she said. "It blew me away that they listened to us and really took [our advice] to heart. They used our input to create the wayfinding outside Fred Hutch. It really gave me a sense that this was not performative."

As a member of the Quality Oversight Committee, Ishida and other patient advisors are asked to weigh in on a variety of clinical issues, from how to prevent patient falls to designing better MyChart alerts to setting up a protocol for patient-provider discussions after lab results are released.

"It's a wonderful opportunity to give your perspective as a patient and to hear from the doctors and the nurses and hear their perspective," she said. "It's a nice way to be a part of a community that gave me so much — and hopefully make it better for others."

‘Patients have to feel they have that agency’

Amer Karim, a 54-year-old Seattle IT professional and kidney cancer survivor, joined the Patient and Family Engagement Program in May of 2024. Unlike Ishida, who joined because her patient experience was smooth as silk, Karim got involved because of snags.

They started after he received a successful full nephrectomy (kidney removal) for his early-stage kidney cancer and a follow-up scan showed a lesion on one of his ribs.

“Within a few weeks, I developed pain in my ribs, and they scheduled a follow-up scan which found more lesions,” he said. “When the doctor ordered a head-to-toe scan, my skeleton lit up like a Christmas tree.”

Karim had dealt with undiagnosed chronic pain for 20-plus years, he said, but this was worse. He went back to medical oncology to eliminate metastatic kidney cancer as the cause of the increasing pain and rapidly deteriorating bones. There, he was diagnosed with tumor-induced osteomalacia, an extremely rare condition that causes bones to soften and grow weak, leading to pain and fractures.

While most osteomalacia is caused by a vitamin D deficiency and treated with supplementation, Karim’s condition — one of less than 5,000 cases recorded globally — was caused by a tumor. But not the cancerous tumor they’d just removed from his kidney — another one that was benign.

Karim’s doctors located and removed what they thought was the problem tumor, and he was told he was cured. But two weeks later, his pain increased significantly, and he began having difficulty walking again.

That’s when he encountered pushback.

“One doctor said, ‘It just takes time,’” he said. “But he didn’t do any tests or scans. And this went on for a year.”

When his bloodwork showed increased osteomalacia biomarkers at a one-year follow-up, Karim insisted on more scans. A second tumor was found, but it was deemed inoperable — not an uncommon issue for patients. Finally, one of his providers proposed trying cryoablation, which uses extreme cold to kill tumors, an experimental treatment that finally worked.

For the first time in two decades, Karim was out of pain. And no longer a patient. But his experience trying to get answers — and the care he needed — prompted him to join the PFE Program to advocate for others.

“Patients have to feel they have that agency of sharing their experience,” he said. “It should be part of the treatment and diagnosis protocol. The difference between my two experiences was so drastic. That year that I waited and was trusting my doctors, I felt like I was being gaslighted.”

As a longtime business consultant, Karim said he seldom pulls punches with clients — “My job is telling CEOs and presidents of large corporations ‘No’” — so he was pleased to see that PFAC wasn’t about rubber-stamping protocols and procedures.

“It struck me as the real thing,” he said. “It’s not a checked box. And it’s been consistent, the feedback we provide is incorporated into how Fred Hutch operates.”

Karim said he appreciated PFAC’s “multiplicity of perspectives” and the fact that the people at Fred Hutch don’t feel they “already know everything.”

“They’re looking at things they’ve been doing for decades and going, ‘I can look at this with fresh eyes,’” he said.

Karim’s experience with an extremely rare disorder has given him fresh eyes, as well, and sparked an interest in biomedical research.

“The majority of patients who are diagnosed with this, their tumors aren’t found,” he said. “They’re just stuck. Dr. [Peter] Thurlow, the radiologist who suggested the cryoablation, is writing a paper about my case, and we talked about getting the patient perspective into it because it’s critical for the discovery process.”

More resources for patients

As executive director and co-founder of the nonprofit Colon Cancer Stars and a 20-year survivor of metastatic colorectal cancer (CRC), Anita Mitchell Isler is used to sharing her voice.

A longtime member of the PFE as well as a national cancer patient advocate, Isler, age 61, regularly lobbies in Washington, D.C., speaks at conferences and collaborates with clinicians across the country to improve CRC screening and patient outcomes.

“There’s a lot we don’t know about early-onset colorectal cancer,” she said. “Yes, we got the screening age lowered by five years, but it took us 20 years to do that. And it’s still not going to save many of these young people.”

Isler knows of what she speaks. When she went to her doctor at age 40 with symptoms, she said, “My PCP blew me off.

“That’s why I’ve stayed active in advocacy,” she said. “Young people are waiting six, nine months, sometimes a year and seeing three doctors before they get a correct diagnosis and by then, it’s late stage. I’m tired of watching people be gaslit and die.”

Isler currently works with Fred Hutch gastroenterologist Rachel Issaka, MD, MAS, who researches ways to improve CRC screening, but said she would love to partner with other Fred Hutch

scientists. Issaka holds the Kathryn Surace-Smith Endowed Chair in Health Equity Research.

“I would absolutely love to work with Dr. Bill Grady on research,” she said. “I know he does research on Lynch syndrome, but I’d love to see more on family history trials, especially with families who don’t have that cluster of mutations. My kids would love that, too. They say mine is genetic, but they don’t know the gene yet. My dad died in his 40s of colon cancer.”

Much like Karim, Isler knows a big part of patient advocacy is asking questions and standing up for oneself. But not all patients are comfortable doing that — especially in an oncology setting.

“You can encourage people and give them information, but they may not be comfortable pushing their doctors to run a test that they need,” she said. “People in community settings do not understand that their general oncologist may not be up to date on the latest studies and biomarker testing for colorectal cancer.”

Isler said she’d love to see Fred Hutch do more research on CRC, particularly more clinical trials. She would also like to see newly diagnosed, late-stage patients’ waiting times improved.

“There’s a lot of work to do,” she said. “We want more people in clinical trials, but the system is not necessarily set up to make that easy, especially if you live far away or the trial has a big waiting list. I also think it helps if patients learn about their disease, so I’d like to see more classes or symposiums on colorectal cancer offered here.”

Isler said she’d also love to see Fred Hutch open an early-onset colorectal clinic.

“We don’t have one on the West Coast and these clinics bring in revenue,” she said. “They also offer more resources for the families affected, who have a different set of needs.”

Survivorship — where a patient transitions from oncology to PCP care — is another area that needs much more attention.

“I feel like it’s lacking,” she said. “Yes, I have a survivorship care plan because I sought that out. And I now have a great primary care physician, but I feel her time is limited and my history is complex. It would be great if we had PCPs who specialized in oncology patients.”

The longtime CRC advocate “definitely” wants to see more patient-focused resources at Fred Hutch and hopes her work with the PFE can help her accomplish this.

“My unique experience attending CRC patients’ appointments over the years keeps me alert to the needs,” she said. “And I’m very happy that they’re now matchmaking patient advocates and researchers.”

Partnering with researchers

Burke leads the effort to match patient advocates with Fred Hutch researchers, in addition to co-chairing the Patient and Family Advisory Council and facilitating focus groups, patient panels and other projects.

The matching aspect of the PFE program, she said, is growing, but slowly.

“We’re continuing to provide resources on how to engage with advisors,” she said. “Not just to check a box, but to actually collaborate with them and listen to them. Patient advocates can help make studies much better and they also bring value with regard to recruitment, retention and access. We learn something from our advisors at every meeting, in every conversation. The staff always comes away with new perspectives or little ‘aha’ moments.”

Burke and team are currently doing “roadshows” around the Fred Hutch campus to help amplify what patient engagement can offer those working the bench (researchers) and the bedside (care providers).

Elizabeth Carosso, program administrator for research operations within the Fred Hutch/University of Washington/Seattle Children’s Cancer Consortium’s Office of Community Outreach & Engagement, needs no convincing.

“Integrating patient voices and insights are essential to shaping research that truly meets real-world needs,” she said.

Carosso regularly helps Fred Hutch clinicians and scientists improve research grant proposals with the OCOE’s Recruitment & Retention Shared Resource, which encourages community and patient input at all stages of research.

Getting patients involved early, instead of as an afterthought or a mandated checked box, can be challenging, though.

“In a lot of cases, the projects’ wheels are already on the road,” Burke said. “We want to continue to spread the word about this program through the organization, so we get patients involved early on, before final decisions are made.”

Carosso could not agree more.

“Embedding patient perspectives at the proposal stage ensures research begins with relevance and ends with impact,” she said.

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