

# Implementing an e-Advisory Council in the COVID-19 Era



Winston Churchill famously remarked, “To improve is to change, so to be perfect is to have changed often.” If this is true, we all must have evolved into a state of “perfection” over these past two years, right? Though I am not actually suggesting perfection, collectively we all seem to have found new and different ways to adapt to significant, unexpected change.

Let me set the stage. I am manager of Patient and Family-Centered Care at Vanderbilt-Ingram Cancer Center, one of 51 nationally recognized National Cancer Institute-designated Comprehensive Cancer Centers. The cancer center is a leader in the prevention, diagnosis, and treatment of cancer. We have a world-renowned team of experts who provide an integrated, personalized, and patient-centered approach to cancer care, including treatment, research, support, education, and community engagement.

Vanderbilt-Ingram Cancer Center believes in a true partnership with our patients. In early 2019 we set a goal to develop and implement a Vanderbilt-Ingram Cancer Center-specific Patient and Family Advisory Council. The larger Vanderbilt University Medical Center boasts three very successful, engaged, and active Patient and Family Advisory Councils that support Vanderbilt University Adult Hospital (1,162 beds), Monroe Carell Jr. Children’s Hospital at Vanderbilt (267 beds), and Vanderbilt Behavioral Health Hospital (106 beds).



Julie Bulger

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Vanderbilt-Ingram Cancer Center is fortunate to have representation on Vanderbilt's Adult Hospital Patient and Family Advisory Council, especially as it relates to speaking up for the needs of our patients receiving inpatient cancer care. But the world of ambulatory care, in which most oncology patients are treated, is unique. Each day we have approximately 700 scheduled patient appointments, including between 30 to 60 new patient visits. (This number reflects patients seen on our main campus and in eight off-site clinic locations.)

### Getting Started

With continued plans for cancer institute growth and expansion, it is imperative to include our patients' and their caregivers' voices, fully and consistently. In 2019, we spent six months developing the cancer center's Patient and Family Advisory Council, including:

- Researching best practices at other academic medical centers
- Identifying and engaging key stakeholders
- Defining the role of the "Advisor"
- Developing onboarding and orientation materials
- Creating a strategic direction, including how to operationalize the meetings
- Collaborating internally to ensure our council aligned with Vanderbilt University Medical Center's mission and other advisory councils.

We wanted to ensure that Vanderbilt-Ingram Cancer Center's newly formed Patient and Family Advisory Council truly reflected the diverse group of patients and families we serve. Having diverse representation is imperative for the Council to inform the cancer center successfully and fully about the experiences and opinions of its patient populations. Thus, we looked at how to include disease-specific diversity, experiences of those receiving different treatment modalities, offsite vs. on-campus care, rural vs. urban care, and patients receiving care via telemedicine, as well as diversity in age, race, sexual preference, education, and socioeconomic status.

We eagerly disseminated our Patient and Family Advisory Council *Call for Nominations* in November 2019. We engaged our faculty for help as they know their patients best. Providers generously responded with nominations for strong candidates; however, unfortunately, the nominees all represented the same

demographic and did not offer the diversity needed. All agreed that we needed to re-evaluate and then re-implement a more targeted recruitment strategy. The plan was to launch the new recruitment effort on March 10, 2020.

### Going Virtual

Like the rest of the world, when the COVID-19 public health emergency heightened, everyone's priorities shifted. Our March 2020 meeting was postponed, but our team believed strongly that the initiative was too vital to lose momentum. We soon convened and decided that if meeting in person was not possible, we would figure out a way for the Patient and Family Advisory Council to meet "virtually."

Looking back, I am amazed at how quickly we pivoted. By the end of March 2020, we partnered with the Vanderbilt University Medical Center's Director of Patient Engagement, Terrell Smith, MSN, RN. She generously offered us an opportunity to tap into the medical center's enterprise-wide Advise Vanderbilt platform at no cost to the cancer center. Launched in 2016, the online Advise Vanderbilt platform helps Vanderbilt University Medical Center leadership improve patient satisfaction and patient and family engagement in care, while making it easier to participate as patient and/or family advisors through the option of responding to targeted survey questions. Most important, Advise Vanderbilt is popular with patients and families and offers data-driven, dynamic customer insights.

In the first cancer center-specific Advise Vanderbilt outreach, we asked three simple questions:

1. Have you or a loved one received care at the Vanderbilt-Ingram Cancer Center in the past two years? (This was followed by a brief description of the mission and goals of the virtual Patient and Family Advisory Council.)
2. Would you be interested in learning more about this opportunity?
3. If so, would you be comfortable sharing your contact information?

Almost immediately we received more than 700 responses. Interested respondents were sent a more detailed survey that asked about their personal experience and collected demographic information. And by the end of April 2020, the Vanderbilt-Ingram Cancer Center's e-Advisory Council was born!

### Fast Forward 18 Months

Vanderbilt-Ingram Cancer Center currently has 274 actively engaged and quite candid e-Advisors. As of October 2020, we have initiated 10 surveys. With all but one survey, we have achieved a 50 percent or higher response rate. Through our e-Advisory Council, we are privy to the thoughts, opinions, and stories of our patients and their families—in real time. To date, we have focused our surveys to specifically contribute to the quality, safety, satisfaction, and experience of our patients and their families and loved ones. And though there are many measures of success, to me the most valuable is the diversity in representation that having a virtual advisory council has brought. Because this is Vanderbilt-Ingram Cancer Center's inaugural Patient and Family

Advisory Council, we cannot “look back” to compare diversity among participants. However, from an initial voluntary set of questions, we were able to track diversity in age, education, gender, LGBTQ identities, type of insurance, languages spoken at home, home ZIP code, and race/ethnicity. It is validating to know we have representation in each of these areas and that, where we are lacking, for example, in representation from Hispanic males, we can work to encourage involvement.

So, what have we learned? First and foremost: Patients and families love to share their opinions! It helps them feel engaged and like a partner in their healthcare decisions. It is vital to share results with Council members so that they can see the impact of their participation. Patients have stopped in our Patient and Family Resource Center and introduced themselves as one of our “Patient Advisors.” They are proud to contribute their insights and perspective. Through their participation, advisors are empowered to use their experience with cancer to drive positive change by sharing their thoughts and experiences to help Vanderbilt-Ingram Cancer Center with continuous improvement.

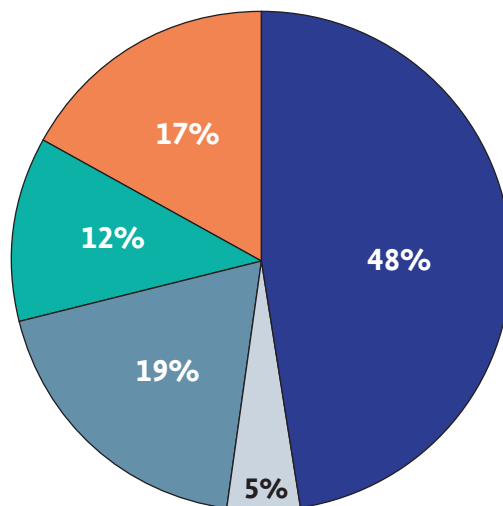
Second, our patients’ voices matter. We cannot claim to be “patient-centered” without an avenue in which to engage in active dialogue with those we serve. We always say, no decisions should be made “about me, without me.” Vanderbilt-Ingram Cancer Center administration appreciates having data to support the need for change, improved service, or, in our case, a large renovation project. For example, we heard from patients that they would prefer more privacy when they are checking out, along with a place to sit down. In response, we renovated two offices in the clinic specifically to provide patients with a more comfortable place to schedule next appointments, scans, treatments, etc. As our larger renovation projects near, we will both revisit patient suggestions and create a survey with more specific questions related to those plans.

Third, it is critical to find champions throughout the institution, as well as the department, to fully utilize the e-Advisory Council. At Vanderbilt-Ingram Cancer Center, Laura Goff, MD, executive medical director, and Karline Peal, MBA, associate operating officer, approve and support all e-surveys. Results are communicated back, and recommendations are made for additional internal leaders to share. Partnering with champions in operations, outreach, marketing, safety, and clinical leadership is imperative. Peal shares that “the Vanderbilt-Ingram Cancer Center e-Advisory Council has been a great asset to us. During the time we can’t bring people together, we have certainly used the direct feedback received via these surveys to drive some very real and positive changes around the cancer center.”

So, what have we accomplished?

- We improved registration check-in efficiency by removing one entire step. Patients are now greeted and checked-in with a Patient Service Specialist immediately (not stopping and waiting for a greeter), which has eliminated long lines.
- Many patients voiced the registration area felt like a “fishbowl” and disliked the exposed feeling. The glass has now been frosted and allows for a more private waiting experience.

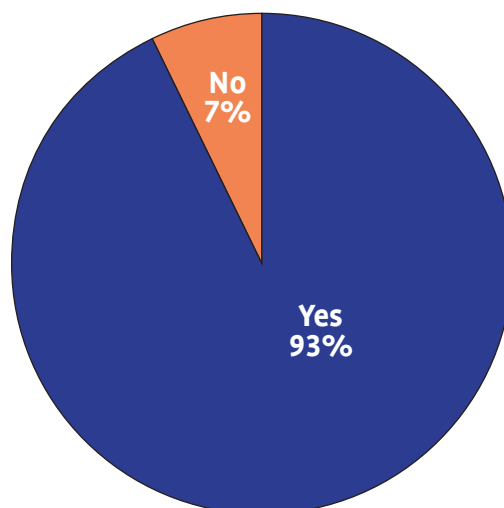
Figure 1. “You’ve just arrived. What is the one thing that strikes you about our check-in process?”



- Friendly staff
- Long Lines
- Too many checkpoints
- Wait times
- Other (please be specific)\*

\*Examples: “I always hope I get one of my favorites who knows my name”; “Lab process is not as efficient as other areas”; “Staff always seem very busy but still take time to make me feel like a person”; and “Check-in is always stressful—I equate it with airport security. I can breathe once I’m past it.”

Figure 2. If we developed an electronic version or a mobile app to check in at registration, would you utilize it?




- After feedback from the e-Advisory Council, we increased the use of text messaging to notify patients of their appointment time.
- A new lab workflow was developed and implemented to decrease wait times.
- We increased communication to patients and families regarding available support services via an electronic “opt-in” newsletter.
- We piloted digital screens in our waiting rooms. These screens will include cancer-specific content (i.e., resources for support in financial assistance, lodging options, nutrition, mental health, tobacco cessation programs, as well as clinical trial outreach and options).

Our e-Advisory Council is a gift that keeps giving. These engaged members are available to offer real-time feedback to questions like:

- You’ve just arrived. What is the one thing that strikes you about our check-in process? (Figure 1, page 35).

- If we developed an electronic version or a mobile app to check in at registration, would you utilize it? (Figure 2, page 35).
- In the waiting room, would you prefer these amenities? Select one (Figure 3, below).
- What types of virtual events would you attend? (Figure 4, below).

In the words of Vanderbilt-Ingram Cancer Center e-Advisory Council Member Myra Curry, “The pandemic has brought so much uncertainty and fear into patients’ lives. I feel as though offering a meaningful ‘seat at the table,’ albeit virtually, has given patients an increased sense of empowerment and value.” Although Vanderbilt-Ingram Cancer Center looks forward to the return of an in-person Patient and Family Advisory Council, the popularity and success of the e-Advisory Council makes it likely that both formats for listening to the patients’ voice are here to stay. 

*Julie Bulger is manager, Patient- and Family-Centered Care, Vanderbilt-Ingram Cancer Center, Nashville, Tenn.*

Figure 3. In the waiting room, would you prefer these amenities? Select one.

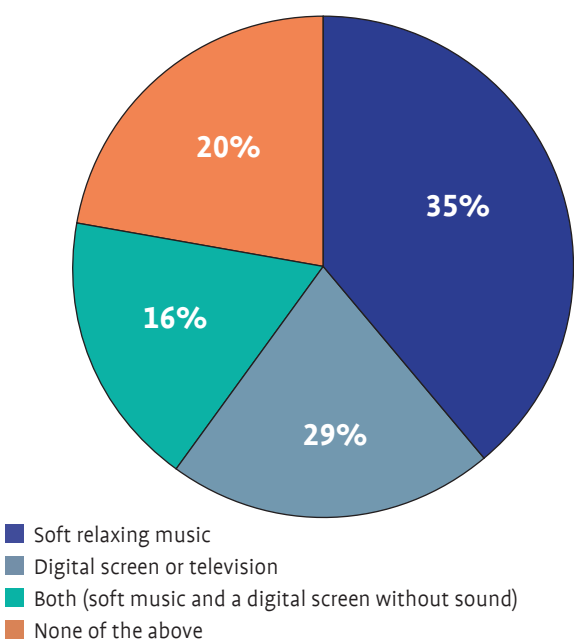
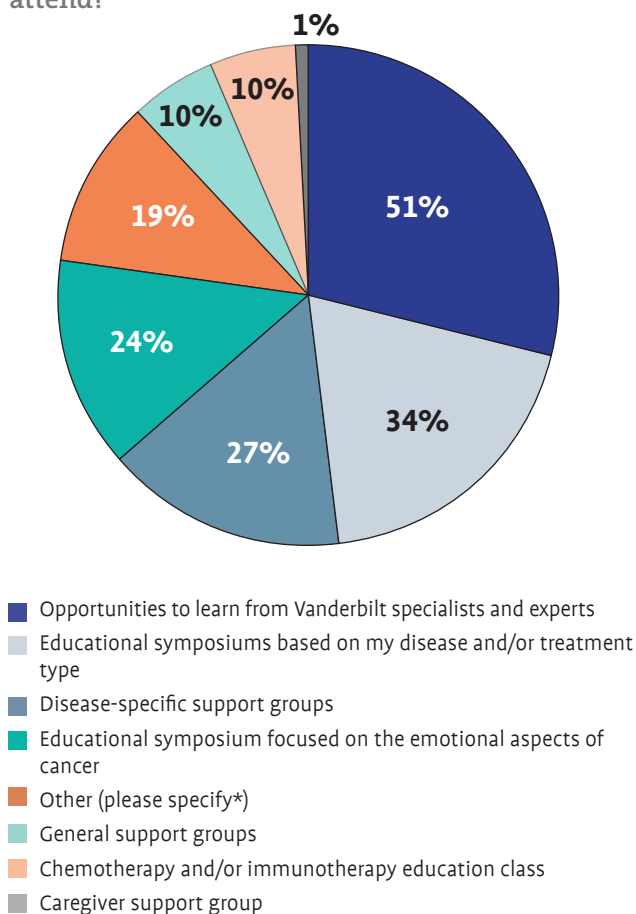


Figure 4. What types of virtual events would you attend?



\*Examples: “Long-term effects/survivorship”; “Mental health—how to connect with a therapist who understands being diagnosed with cancer”; and “Advances in cancer research—immunotherapy and oral chemo.”