

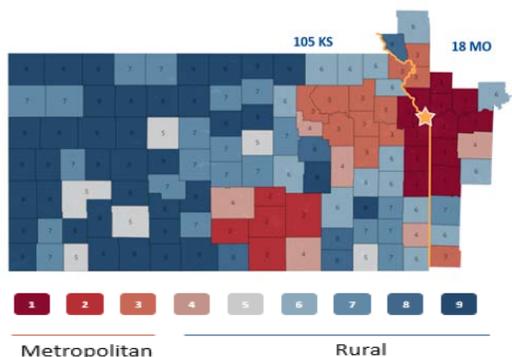
Community Outreach and Engagement The University of Kansas Cancer Center

Catchment Area

The University of Kansas Cancer Center is the only academic cancer center in the state and is a consortia between the University of Kansas Medical Center, The University of Kansas in Lawrence, Children’s Mercy, and Stowers Research Institute. Located in Kansas City, a city that straddles Kansas and Missouri, the KU Cancer Center catchment area includes all 105 counties in Kansas and 18 neighboring counties in western Missouri (Figure 1). The total population in the 123-county catchment area is 4.5 million. In 2017, that area had 22,000 cancer diagnoses and 8,500 cancer deaths.

A unique aspect of the catchment area is the rurality of Kansas and western Missouri. Of the 123 counties, 96 (78%) are classified as rural based on the Rural-Urban Continuum Codes (RUCC) 4-9.

Figure 1. KU Cancer Center Catchment Area by RUCC



Community Engagement Focus

This community engagement training program was designed for basic scientists focused on the skills needed to build collaborations and communications between the researchers and patient research partners.

At a Glance

KU Cancer Center has a strong history of community outreach and engagement (COE) and sought to design a program that will strengthen collaborations between basic scientists and patient research partners. The nine-month didactic and experiential program focused on building an understanding of community engagement, enhancing communication, and building collaboration between researcher and patient partner dyads. Eleven researchers were selected to participate in the program, and each was paired with a patient research partner.

Collaborators

PIVOT: In 2017, KU Cancer Center created Patient and Investigator Voices Organizing Together (PIVOT) to provide a formal mechanism for patient advocates to collaborate with cancer center scientists to inform research. Currently, PIVOT has 120 trained patient research collaborators who are diverse in terms of race, ethnicity, age, cancer experiences, and socioeconomic background; they live across the catchment area in rural, urban, and suburban communities. PIVOT research partners are either previvors, survivors, and/or co-survivors and can share a collective cancer experience to influence research throughout the continuum. PIVOT helps ensure cancer research is relevant to patients by (1) including patients’ voices in every step of research; (2) promoting meaningful collaborations between researchers in all three cancer center research programs and the patient partners; and (3) collaboratively developing education and training for patients, families, caregivers, and researchers.

Cancer Biology (CB): The CB program is one of three formal research programs at KU Cancer Center.

The overall scientific goal of CB is to understand normal and cancer cell behavior to ultimately reveal useful biomarkers and new cellular targets for cancer therapeutics and prevention.

Drug Discovery, Delivery and Experimental

Therapeutics (D3ET): The D3ET research program integrates a broad range of research areas that contribute to the discovery of new cancer therapeutic agents as well as novel approaches to effective drug delivery; the development of drug products and diagnostics for the treatment and prevention of cancer; and the evaluation of these medical innovations in hypothesis-driven experimental therapeutics trials.

The Approach

Recruitment

Basic Scientist Selection: From 18 scientist applications, 11 researchers from the CB and D3ET programs were selected to participate in the Training Program for Basic Scientists. Selections were made ensuring diversity in age, gender, race, ethnicity, experience, stage of career, research focus, KU Cancer Center research program, and location. The inaugural class represented 10 faculty members and one fellow, who are cancer center members from the University of Kansas Medical Center—Kansas City and Lawrence, Stowers Research Institute—Kansas City, and Children’s Mercy—Kansas City campuses.

Patient Research Partners: From 25 PIVOT patient research advocate applications, 11 were selected to represent diversity in age, gender, race, ethnicity, and lived cancer experience. The project team was intentional in matching cancer experience with researchers’ interests.

Methods

The program included didactic and experiential components. The curriculum had three main themes: (1) COE principles; (2) development of skills for scientific communication to a lay audience; (3) team science principles for collaboration between the scientist and

patient research partners. In addition to the monthly group meetings, dyads were encouraged to meet regularly throughout the nine-month program. Each dyad was given a list of potential research activities to engage in during their monthly meetings, such as in-person or virtual lab tours, participating in a lab meeting, attending KU Cancer Center seminars together, working on a proposal, and attending an advocate’s community meeting. Homework such as co-creating a presentation or co-writing a lay abstract was also assigned.

COE Principles and Methods Workshop (Module 1):

This module focused on the KU Cancer Center catchment area and patient and community engagement principles. The first hour reviewed the structure of the cancer center’s outreach efforts, priorities based on catchment data, and community needs. The KU Cancer Center Community Advisory Board and population-specific board chairs presented on how to engage with their individual boards.

Communication Skills (Module 2):

The Alan Alda Center for Communicating Science delivered two virtual workshops. “Creating Connections” was focused on basic communication strategies. “The Essentials” was focused on making messages understandable and memorable.

Team Science (Module 3):

This module focused on integrating team science principles and building on the dyad strengths. Collaborations were launched with a Clifton Strengths assessment and discussion, followed by meetings (pairs and as a group) to specifically work on utilizing the strengths of each pair.

Promoting Patient Partnership Among Researchers:

At the conclusion of the program, each pair was invited to present their research at KU Cancer Center’s Research Week. Members of the cancer center were able to observe how the pairs collaborated, demonstrating the value of patient partnerships. One pair presented at the cancer center’s CB Program Meeting; another pair presented at the 2021 Translational Oncology in Academia and Industry Symposium. The cancer center also hosted a pair on their Facebook Live series **Bench to Bedside**.

Bench to Bedside is a weekly series that follows the latest

news and developments related to cancer care, clinical trials, and research.

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Partnering with PIVOT has been immensely helpful with improving both my science and how I describe my research discoveries to the public. I have been working with Tonia for the past year. She is a cancer survivor and a phenomenal individual who has not only been supportive of my work but has helped me to make it better!

Greg Gan, MD, PhD

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Project Outcomes

As part of the extensive evaluation, we adapted the Core Competencies for Public Health Professionals Tier 1 Communication Skills (Public Health Foundation 2014 version). Pre-program, the researchers rated their ability to communicate orally with community members as aware but limited knowledge (10 percent), knowledgeable (70 percent), or skilled (20 percent). Post-program, the researchers indicated their ability to communicate orally as skilled (70 percent) or proficient (30 percent). The advocates rated the researchers' ability to communicate orally with community members pre-program as aware but limited knowledge (9 percent), knowledgeable (18 percent), skilled (18 percent), or proficient (55 percent). Post-program, the advocates rated the researchers' ability to communicate orally as aware (9 percent), skilled (18 percent), or proficient (73 percent).

Researchers have incorporated the advocates in funding research and proposals, successfully applied for a cancer center pilot grant, and submitted a letter of intent to the Department of Defense that was chosen for full proposal submission.

Implementation Guidance

Implementation Tips

Patient research partners are experts in their cancer experience. It is key to reimburse them for their time spent engaging with researchers.

To encourage researcher engagement, we developed a selection process. The opportunity was announced by our cancer center director at our annual symposium, which created excitement and demonstrated program value to KU Cancer Center.

The cancer experience is often traumatic. We created a workshop with our licensed clinical social worker to support the advocates' and researchers' emotional responses to their traumatic experiences.

In the future, we plan one-one coaching by the COE office to support the research pairs' connections and collaborations. Researchers' careers can be fluid; as such, we had two researchers who changed locations mid-program. Preparing the advocates for potential transitions is key in supporting them.

Sustainability Plans

We plan to shorten the curriculum based on evaluation results, and will offer the program annually.

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Partnering with Bret and being a part of the program was an eye-opening experience. I am grateful for all the hard work and passion Bret and his team put into their research. I was honored to use my experience as a cancer survivor to help his research team and use my voice to contribute to the fight against cancer.

**Rebecca Burns,
Patient Research Advocate & Breast Cancer Survivor**

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Patient Partnership: Rebecca Burns and Dr. Bret Freudenthal Patient Partnership: Tonia Yelder and Dr. Greg Gan

Find Out More

To learn more about PIVOT and KU Cancer Center activities, please visit: <https://www.kucancercenter.org/research/give-back/patient-research-advocacy>

Instagram: @pivotkucc

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Contact

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Community outreach and engagement (COE) activities across the translational research continuum

National Cancer Institute (NCI)-designated cancer centers' COE efforts should span all cancer center programs, including basic, clinical, translational, and population research. In FY20, NCI issued a call for Cancer Center Administrative Supplements to support COE activities that focus on either basic science or the translation of evidence-based interventions into community practice. The long-term goal of the supplement initiative is to build capacity for cancer centers' COE programs to adapt and implement evidence-based programs and successfully collaborate with cancer center investigators across research programs and in partnership with community members. To learn more, visit us at: <https://cancercontrol.cancer.gov/research-emphasis/coe>