

PIVOT

PATIENT AND INVESTIGATOR
VOICES ORGANIZING TOGETHER

THE UNIVERSITY OF KANSAS
CANCER CENTER

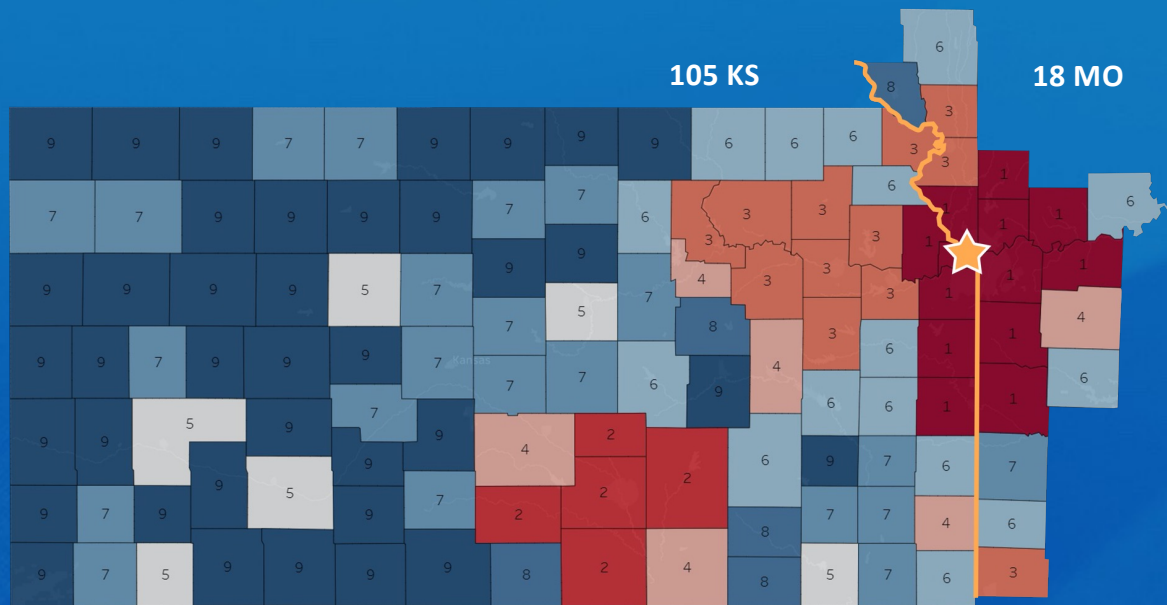


Overview

- **KU Cancer Center and community outreach & engagement**
- **Why involve patient research advocates?**
- **PIVOT vision and training**
- **PIVOT Rapid Reactor Team (RRT)**
- **Outcomes and lessons learned**

KU Cancer Center Catchment Area

	Catchment (4.5 million)	USA
Rural	24.0%	19.3%
White	85%	76.3%
Black / African American	8%	13.4%
Asian American	3%	5.9%
American Indian	1%	1.3%
Hispanic	10%	18.5%
% in Poverty	11.2%	11.4%
<65 without insurance	10.6%	11.1%



Rural Urban Continuum Code (RUCC 2013)



Metropolitan

Rural

KU Cancer Center Community Outreach & Engagement

- 1 Identify and monitor
- 2 Collaborate with community stakeholders
- 3 Stimulate and support research
- 4 Drive, disseminate and implement cancer control activities



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Community Advisory Board



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Community Engagement

Community Advisory Board: meets 4x/year

- Overarching advisory board with representation from each stakeholder group
- 18 individuals representing a diversity of cancer experiences, skills, community connections, geography, culture, race, ethnicity and gender



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Community Advisory Board



Network of 17 health care facilities
and community cancer centers



Network of 90 primary care
practices



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Roy Jenson
KUCC Director



Cheryl Jernigan
Lead Advocate



Kim Kimminau
Lead Researcher



Scott Weir
Director, Institute for
Advancing Medical Innovation



Hope Krebill
Executive Director
Masonic Cancer Alliance



Dan Dixon
Co-leader, Cancer
Prevention & Survivorship



Community Advisory Board & PIVOT Roles

Community Advisory Board

- Priority setting
- Policy development
- Outreach and engagement guidance



PIVOT Patient Partners

- Grant Reviews
- Planning
- Development
- Implementation
- Oversight
- Reporting Results/Dissemination



Types of Advocacy



Support



Outreach & Education



Policy



Fundraising



Research



Who are patient research advocates?



- Previvors, Survivors & Co-Survivors
“Lived” cancer experiences
- Committed to representing patient concerns & perspectives
- Tied to the broader community of cancer survivors/co-survivors
- Individuals who are able to share a *collective* patient perspective

Why Involve Patient Research Advocates?



- Ensure patient focus & relevance
- Add a human face & sense of urgency
- Provide real life, diverse, insightful expertise
- Spur innovation

Attributes of a Great Research Advocate

- Desire to make things better for patients
- Strong communication skills...a “voice” for patients
- Ability to represent “all” patient ...not just their story
- Independence from the researcher & his/her institution
- A drive for knowledge...
- Ability to work collaboratively with others

Inaugural Patient Development Team

patient-driven!



Cancer Experiences

Anal	Leukemia
Brain	Lymphoma
Breast	Melanoma
Colorectal	Ovarian
Esophageal	Pediatric
Head & Neck	Prostate

High-risk through
metastatic

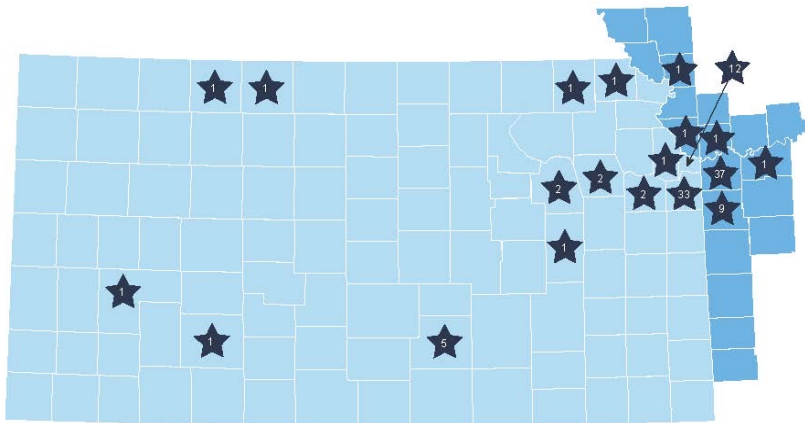
September 2016



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130+ PIVOT Members

PIVOT MEMBERSHIP MAP



★ Number of PIVOT members in Kansas and Missouri counties

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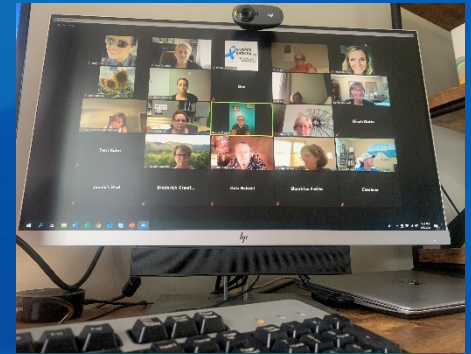
PIVOT
PATIENT AND INVESTIGATOR
TRIAL NETWORK



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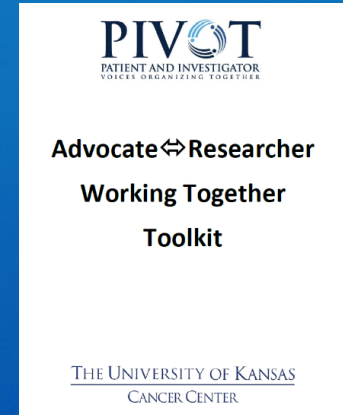
PIVOT Patient Advocate Trainings

- Cancer Research 101
- NIH Biosketch for Advocates
- Translational Research Timeline
- KUCC Response to COVID-19
- Effective Research Partnerships
- Clinical Trial Office - Reviewing an Informed Consent
- Grant Review Team Training



Additional Advocate Opportunities

- Advocate ↔ Researcher Toolkit
- Rapid Reactor Team Toolkit
- PIVOT YouTube
- Bench-to-Bedside Facebook Live
- Newsletter: highlights KUCC events & advocacy opportunities
- KUCC Annual Research Symposium/Poster Walks
- Private Facebook Group



If you build it, they will come...



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Immediate
Relevant,
Patient-Honed
Feedback!



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Researchers: Would you like patient feedback?



Rapid Reactor Team

- Immediate feedback to KUCC's researchers in a semi-structured, conversational setting
- A team approach to get patient research advocates' perspectives on all aspects of your research plan, including the research question
- Provides an opportunity to build relationships with patient partners and deepen your understanding of population of interest

Mondays or Thursdays from 5-6PM.

Sessions are scheduled upon researcher request

To schedule a session or for additional information, please contact us!

CALL

913-945-6873

EMAIL

PIVOT@kumc.edu

<http://www.midwestcanceralliance.org/PIVOT>



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Rapid Reactor Team (RRT)



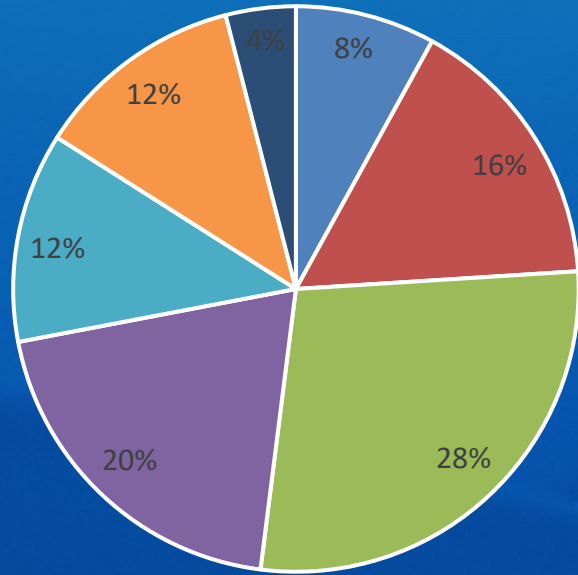
Researchers:

- Structured PowerPoint template
- Virtual Presentation: 10-15 minutes
- Advocate discussion: 45 minutes

From a *patient-focused* perspective:

- Prioritize research topics
- Hone research questions & strategy
- Enhance the study's relevance
- Strengthen recruitment & retention

RRT: Researchers' Evaluation



- Understand patient voice
- Increase sensitivity to patient
- Feedback on feasibility
- Project appropriateness
- Recruitment

PIVOT Researcher Engagement



“As a scientist, my perception of patient care is highly influenced by my research in the lab, hence, there is limited interactions with patients. The opportunity to interact with PIVOT and to share my research findings with them during the RRT session was beneficial in helping me to see how my research can potentially benefit patients. It also gave me the opportunity to refine/redefine my research questions based on insightful and thoughtful feedback from PIVOT.”

*Joan Lewis-Wambi, Ph.D.
Associate Professor-Cancer Biology*

Identify Patient Partners



Researcher Tools

- Advocate ↔ Researcher Working Together Toolkit
- Ongoing Webinars
- 1:1 Coaching
- COE Training Program for Basic Scientists
- Facilitated discussion
- Lay summary and community presentation review



**Advocate ↔ Researcher
Working Together
Toolkit**

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Supplement Outcomes

- Improved communication skills
- Incorporated advocates in funded proposals
- Lasting Partnerships



Outcomes



- Engaged >80 Researchers
- Supported 65 Proposals
 - KUCC Pilot Grants
 - Department of Defense Grant
 - NCI-NIH RO1
- Hosted 47 RRT Sessions

Lessons Learned

- Partnerships require intentional interactions.
- Research topics can be re-traumatizing for advocates.
- Research careers are fluid and involve changing institutions.

Acknowledgements

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Thank you to the PIVOT
Members, KU Cancer
Center Researchers,
Community Advisory
Board Members,
PIVOT, and MCA Staff
and Faculty



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Reaching more people.
Saving more lives.
Together.

