

The Value of Community Outreach and Engagement to Busy Basic, Clinical and Population Health Scientists

Dialogue Facilitator: Melinda Butsch Kovacic, MPH, PhD

UCCC Associate Director of Community Outreach and Engagement

Professor and Associate Dean of Research, UC College of Allied Health Sciences

Professor, Department of Pediatrics, UC College of Medicine

Division of Asthma Research, Cincinnati Children's Hospital Medical Center



Personal Career Trajectory

Training (1996-2002)

Basic Science Research Focus

- Retroviral biology/biochemistry

Early Faculty Years (2006-2014)

Clinical Research Focus

- CCTST KL2 and NHLBI R21 (2009-2011)
- NHLBI R01 (2011)
- CCTST Community Partner Grant (2012)



Later Faculty Years (2014-present)

UC Administrator with a Community-Based Research (CBPR) Focus

- Building trust by working WITH lower income, often minority communities to co-created research tools and materials to support mutually beneficial collaboration
- NIGMS Science Education Program Award/R25 - We Engage for Health (WE4)
- NCI Undergrad Cancer Researchers/R25 - Cancer Research Scholars Program

My Community Partnerships

I began partnering in 2011; thereafter expanded my research to use community-based research approaches:

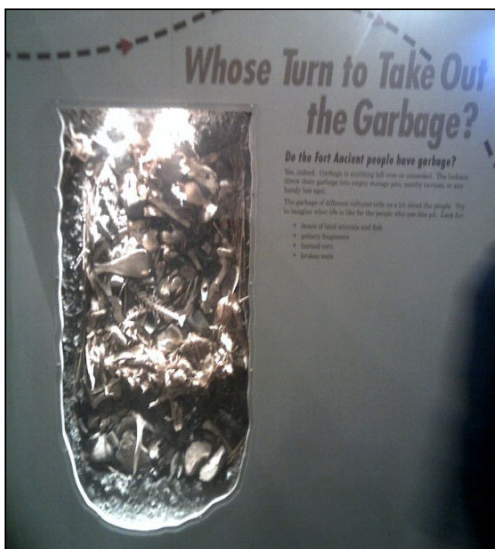
- **The Seven Hills Neighborhood Houses Center**, a social service agency and community center in Cincinnati's West End (Alexis)
- **Consider the Poor**, an advocacy, consulting, training and serving ministry educating the public about poverty in Cincinnati (Sherman)
- **First Ladies for Health**, a Cincinnati, faith-based, nonprofit focused on empowering people to make informed health choices (Dena)
- **Keep Norwood Cool**, an environmental advocacy group (Dana)
- **Others**: Cincinnati and Norwood Health Departments, area schools (Norwood, Oyler), Breakthrough Cincinnati, etc.



2011-2012 PhotoVoice Project



Cameras given to children
8-14 years old to use
photos to express their
opinions



Title: Old garbage where it should be
Health Topic: Body and Heart

"My photo shows garbage from long ago.... Today, people litter and put garbage everywhere on the ground around here ... People are just lazy or don't care.... To help, I can pick it up and put it in the trash. I can tell others not to litter... I don't want to be lazy. I want to be successful and not disappoint my family by giving up my dreams.... If there is a lot of garbage, it can pollute the air and that can affect your lungs. I need to be able to breathe and hold oxygen ..."

Goal of ALL Human Subjects Research *(and indirectly, the basic research that supports it)*

To provide evidence and insights that can be used to improve health outcomes

- Description
- Prediction
- Explanation/understanding
- Control
- Application

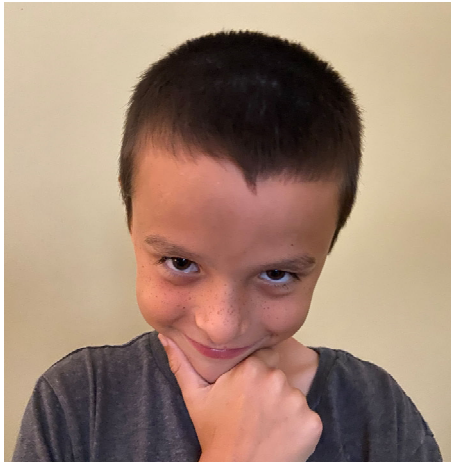




Ethics of Human Subjects Research ([HSR](#))

- Social and clinical value
- Scientific validity
- Fair subject selection
- Favorable risk-benefit ratio
- Independent review
- Informed consent
- Respect for potential and enrolled participants

Value of Participant Perspective



- Researchers' priorities differ from patients and study participants; research therefore lack pragmatism and patient centeredness. I know how it feels to be a research participant and a parent of one....
- Engagement via consultation, collaboration and/or publicly led efforts to better understand their perspectives can help researchers reduce research participant burden and improve participation and retention of more diverse groups, particularly in clinical trials, by tailoring or targeting their studies
- It can also ensure our research reflects the needs of diverse populations from across our catchment area

gexl.q irx\$vie

• xli\$vie\$j\$sm)Cs{ r\$ix2\$vsq \$ lmg1\$swtnepw\$
texirw\$swglssp\$xyhirw\$vie\$ve{ r2



Greater diversity in research participation is critical to ensuring health equity for all

- Participants in research should reflect the diversity of our culture and conditions, considering race, ethnicity, gender, age, abilities, etc.
- The lack of diversity among research participants has serious ethical and research consequences.
- This includes impeding our ability to generalize study results, make medical advancements of effective therapies, and it prevents some populations from experiencing the benefits of research innovations and receipt of high-quality care
- Community engagement is a method to improve diversity and be more inclusive in research.



What is Community?

- Community is defined as a group of people living in the same place or having a one or more characteristics in common.
- Examples of community include:
 - people living in Lower Price Hill,
 - the LGBTQI+ community,
 - people fighting colon cancer,
 - Students attending the University of Cincinnati,
 - public health researchers.

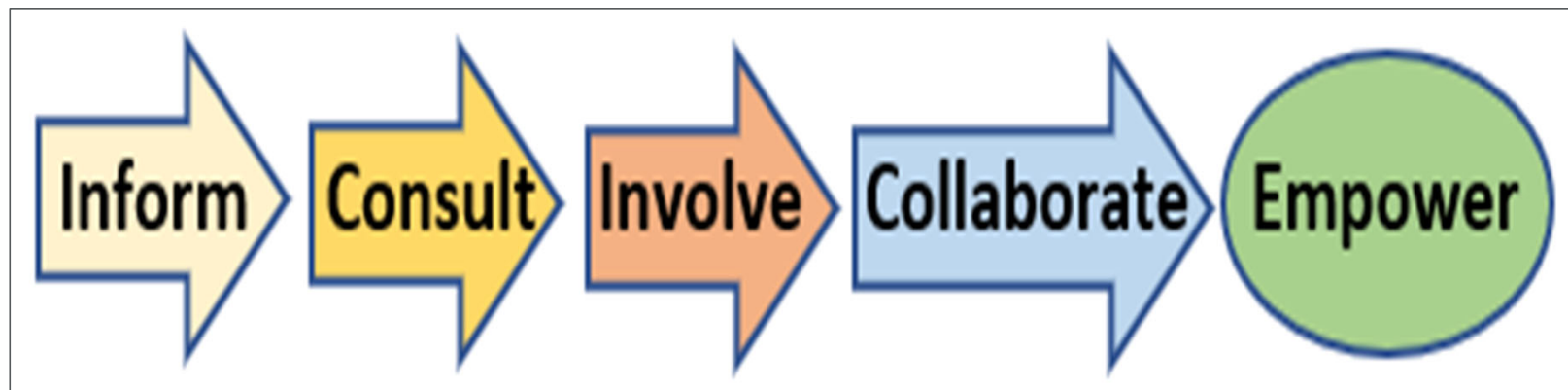


Access: For Mutual Benefit

- COE allows researchers greater access to community groups (e.g., people at risk, patients living with illness, caregivers and families who have lost a loved one, underserved groups, etc.).
- COE increases community members' access to education, prevention, screenings and opportunities to test interventions that may reduce their disease risk, reduce their mortality, increase their survival, and improve their overall quality of life.



Levels of Engagement

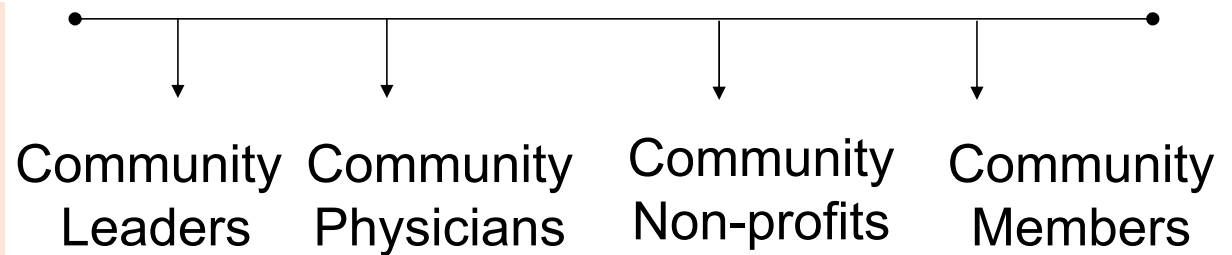


Community engagement particularly activities done WITH community also:

- leads to products and materials that would otherwise go unrealized if co-created with community!
- encourages diversity in the scientific workforce,
- is noticed and respected by local businesses and philanthropists

Different Levels of Community to Engage With

- Community Leaders
 - Individual Representatives
-
- Focus Groups/Interviews
 - Advisory Boards
 - Trained Advocates



Goal:
To Improve health
and science literacy
in the community



Don't Go At It Alone!!!

Leverage COE institutional resources:

- UC Cancer Center Community Outreach and Engagement – Melinda Butsch Kovacic
- CCTST Community Engagement – Lori Crosby
- UC Community Change Collaborative – Farrah Jacquez, Kathie Maynard & Jess Kropzcynski
- UC Center for Environmental Genetics Community Engagement Core – Nick Newman
- UC Center for Public Engagement with Science (PEWS) - Angela Potochnik
- UC Ethics Center – Andrew Cullison
- The Cincinnati Project - Michael Griffin
- CCHMC Community Outreach – Monica Mitchell
- UC Urban Health Pathway – Dena Cranley
- UC Urban Futures - Kathie Maynard
- UC Public Health Programs – Regan Johnson
- UC Experiential Learning – Michael Sharp

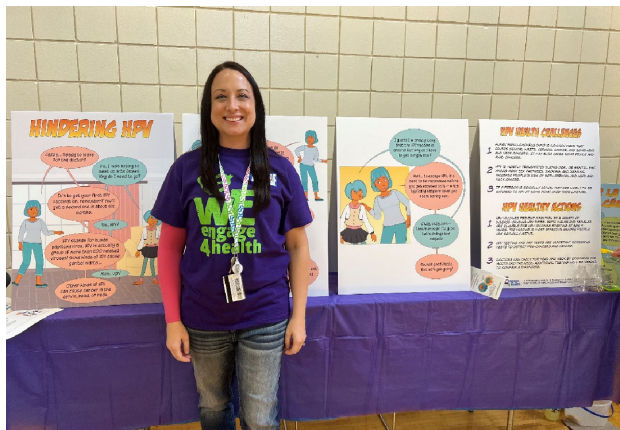


Easy Ways to Engage

- **Community Outreach Discussions** – a science talk with the goal of discussion
- **Event Attendance** - health fairs, volunteer or celebration dinners, road races and rides, and fundraisers – and more!



Community Health Fairs



Advisory Boards

“...studies increasingly show that when health care administrators, providers, patients, and families work in partnership, the quality and safety of health care rise, costs decrease, and provider and patient satisfaction increase”

Willis, R., Krichten, A., Eldredge, K., & Carney, D. (2013). Creating a patient and family advisory council at a level 1 trauma center. *Journal of Trauma Nursing*, 20(2), 86-88.



West End Community Research Advisory Board



- Established in June 2016, monthly
- Humanizes research in the West End.
- Engage researchers to ensure they support the West End's health goals in addition to informing research
- Make research easier and more understandable to community members
- Ensure research is mutually beneficial
- CCTST provides \$30 incentive/meeting
- Coordinator: Julie Wijesooriya

Research Advocates Program

- Research Ready is an outreach program offered by Research Advocates (CRAs) to family, friends and community members to help them become “Research Ready” using the Research Ready story and Discussion Plan

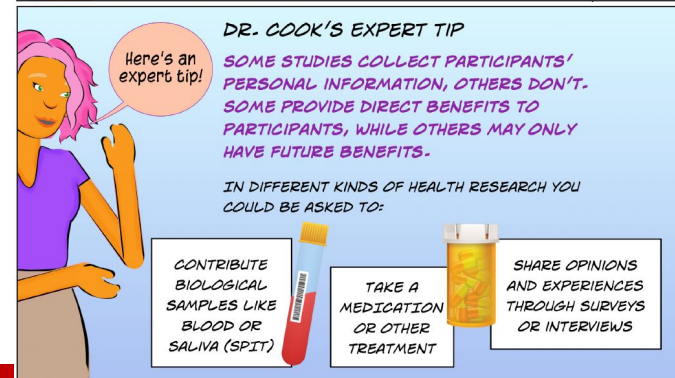
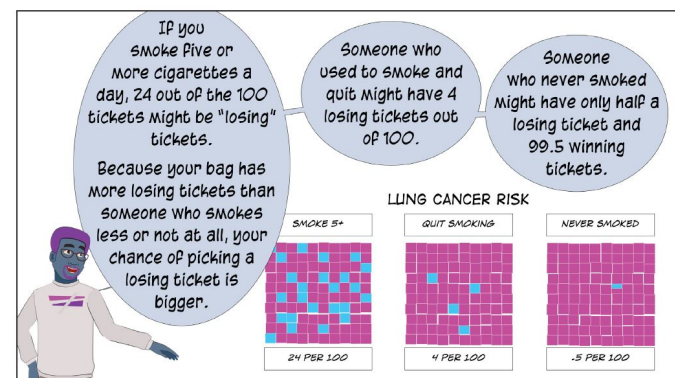
Being “Research Ready” means understanding the 3 P’s.

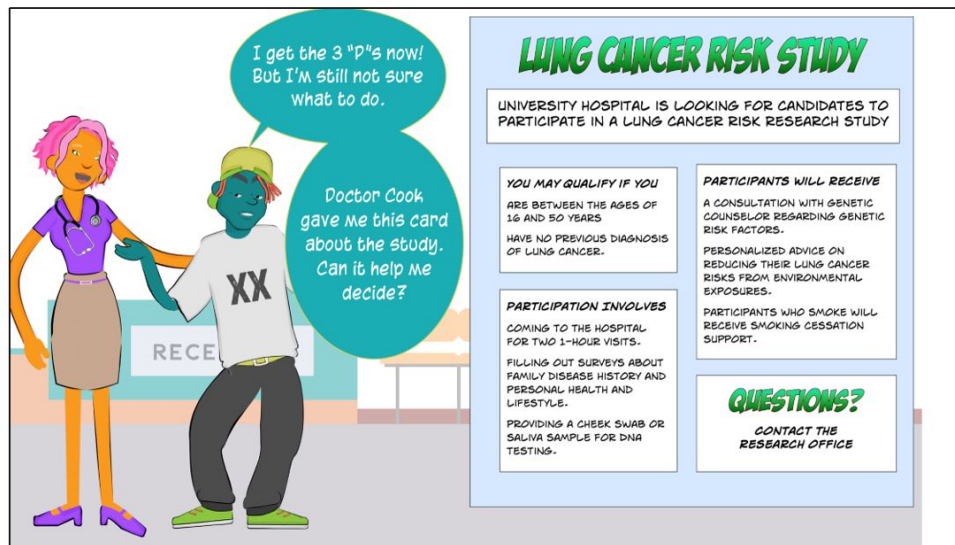
Purpose: What is the purpose of health research?

Protection: How are people kept safe when they participate in health research?

Participation: Why should people participate in health research?

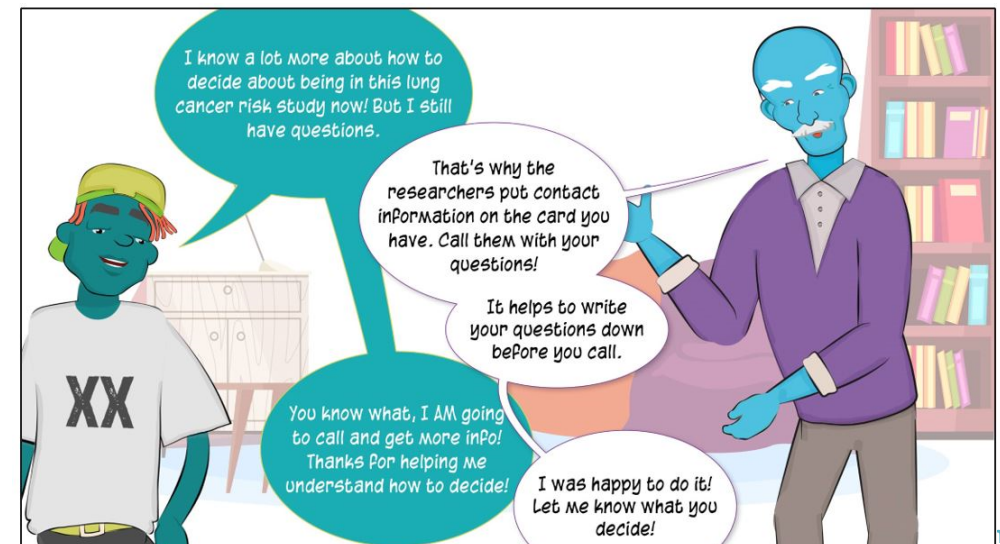
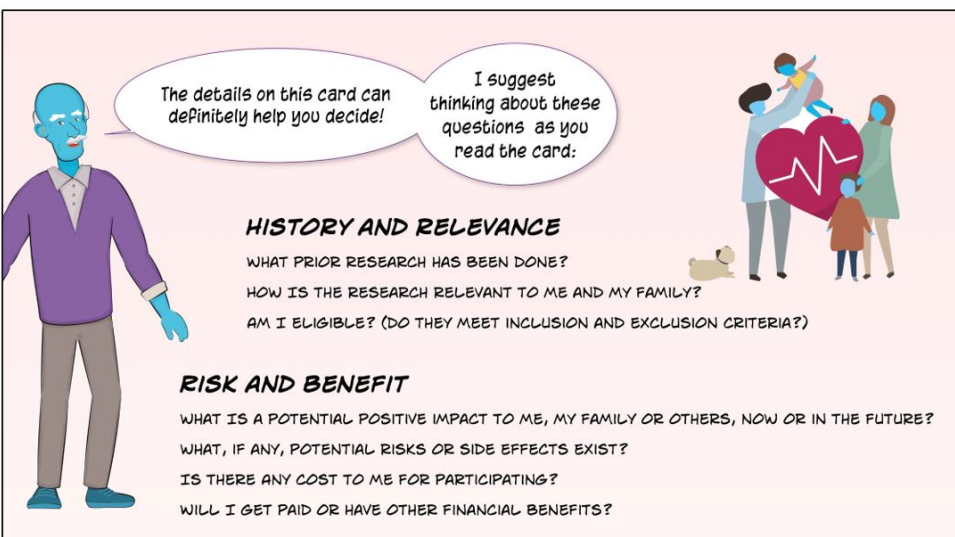
- CRAs are TRAINED community representatives with a personal connection to communities and/or specific cancers; they are paid for their efforts
- CRAs can work with traditionally trained researchers to help them tailor their community messaging to spotlight their studies for consideration.





Research Ready

- Helps attendees to know WHAT to consider when choosing to participate in research and WHY
- Encourages them to ask questions of researchers



Action Steps

How will we gain or maintain the positive results from focusing on this left pole?
What? Who? By When? Measures?

- Make and test SOPs in a subset of potential community participants
- Offer educational materials with study requests
- Pull first 20 responses and evaluate quality with community
- Consider ethics and plan publications with community
- Work with community to co-create community-friendly dissemination tools and pubs in a timely fashion

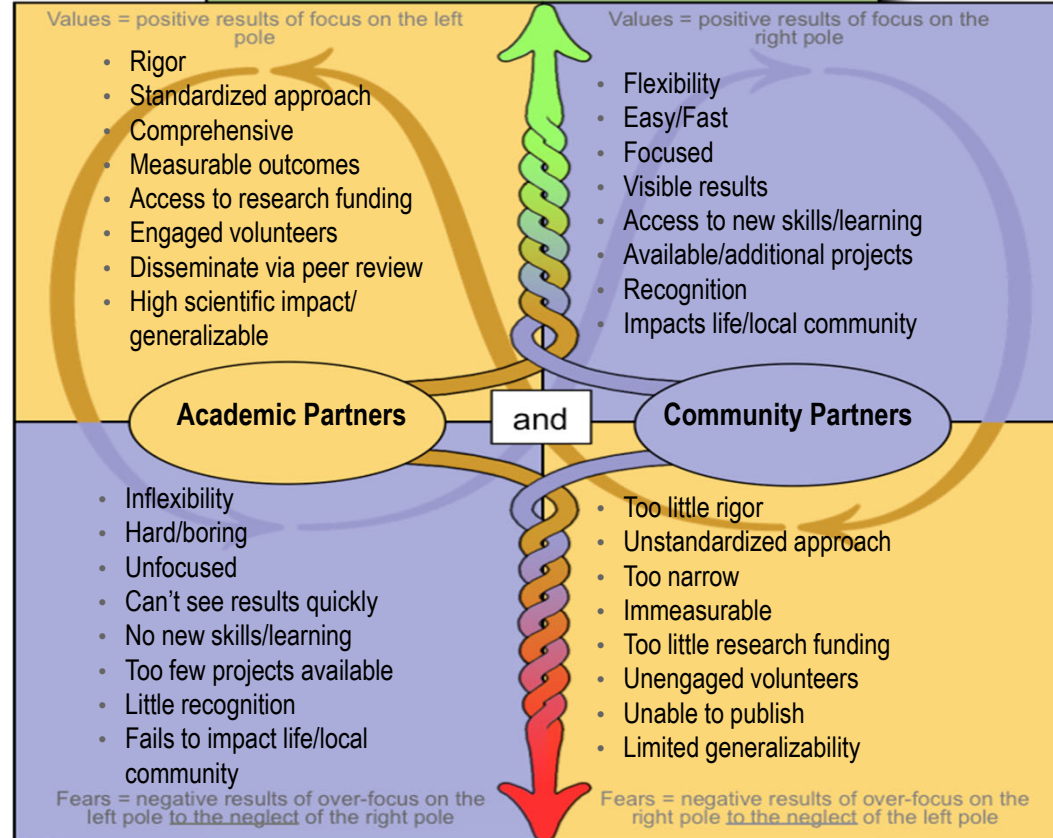
Early Warnings

Measurable indicators (things you can count) that will let you know that you are getting into the downside of this left pole.

- Sub-standard responses on early data results
- Limited repeat CS
- Limited referrals
- Missing regular report outs

Greater Purpose Statement (GPS) - Why leverage this polarity?

Sustainable, Effective Community Research



Action Steps

How will we gain or maintain the positive results from focusing on this right pole?
What? Who? By When? Measures?

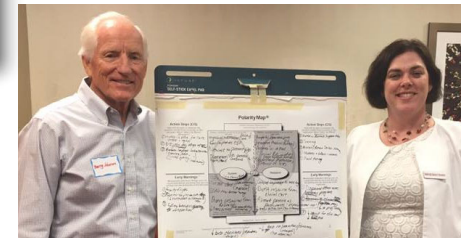
- Work with community to co-create the study
- Broadly ask for feedback
- Include challenges or incorporate incentives to motivate community members; encourage referrals
- Regularly recognize community or show appreciation
- Focus scope and make study participation accessible to diverse groups

Early Warnings

Measurable indicators (things you can count) that will let you know that you are getting into the downside of this right pole.

- Lack of participation
- Feedback showing boredom
- Missing data; incomplete; mistakes
- No community buzz

Polarity Co-Founder: Barry Johnson



What is Polarity Thinking?

TEDxUCincinnati

<https://www.youtube.com/watch?v=ws2p8fZnMKM>

Thank you!

Questions?

