

# Harnessing the Power of the Participant Perspective Through Research Participant Advisory Groups

Julie Wijesooriya, MPA; Melinda Butsch Kovacic, MPH, PhD; Rebecca Harper, DNP, RN, CPN

## Background

From research design to dissemination, there is potential disconnect between the researcher and participant that results in deficiencies in the research process and outcomes. Whether it is recruitment struggles, an ineffective consent process, or broader concerns about trust in research, the participant/community perspective and engagement is lacking in research settings.

Two complementary Research Participant Advisory Groups (RPAGs) were created to improve, grow and support structured collaboration in a mutually beneficial way.

### Research Participant Advisory Council (RPAC)



### Community Research Advisory Board (West End C-RAB)



The impact of the two groups include:

- Influencing health research across Cincinnati's Academic Health Center, including researchers at Cincinnati Children's Hospital Medical Center (CCHMC) and the University of Cincinnati (UC)
- Elevating the voice of and humanizing research participants and underserved communities in research
- Emphasizing the importance of participant/community engagement in attaining the research goal of achieving better health outcomes

## Program Goals

RPAGs give potential research participants and community members the opportunity to first learn about and later inform research processes through direct engagement with clinical and community-based researchers. Researchers too learn the critical value of participants' and community's perspectives for their studies.

### RPAC

- Humanize the face of research
- Provide researchers guidance on how to improve research processes, with a focus on the participant experience
- Establish best practices and improvement initiatives



Acknowledgements: We would like to thank all the members of the RPAC and West End C-RAB for their participation.

### West End C-RAB

- Humanize the face of research in the community
- Engage researchers in supporting the West End's health goals while collecting study data (via CBPR)
- Make research easier and more accessible to community members
- Guide the types of research offered in the West End neighborhood
- Encourage mutually beneficial academic – community partnerships



## Program Description

### RPAC

- Meet monthly for 1 ½ hour meeting at CCHMC, preceded by dinner
- Focused on the overall research participant experience at CCHMC
- Research participants and family members ages 14 to 66 years (n=20)
- Supported by: Research Community Liaison (JW), Research Coordinators/Nurses, Research Marketing, Research Education
- Compensated \$30 via ClinCard each meeting

### Collaboration with 12 researchers on their studies:

- Genomics video/decision-making tool\*
- When/how to approach for in-patient and surgery research studies
- Hearing study design
- EFIC Studies\*



### 12 institutional-wide improvement/educational initiatives:

- Electronic participant screener in REDCap
- New informed consent template (Key Information section)
- Research content on in-patient GetWell TV Network
- CCHMC main biobank creation/marketing\*



### West End C-RAB

- Located at a community center, Seven Hills Neighborhood Houses, in West End, an underserved Cincinnati neighborhood
- Focused on community health and research
- Adolescent and adult community members (n = 15), age 16 to 78
- Support Staff: Research Community Liaison (JW), Faculty Liaison (MBK), Seven Hills Liaison, CCHMC staff member/West End resident
- Meet monthly for 1 ½ hour meeting, preceded by dinner
- Compensated \$30 for their time

### Long-term partnerships (design, implementation, dissemination) with 4 researchers offering programming addressing community needs:

- Health Promotion and Citizen Science Education
- Intervention for African American Women and Stress
- Healthy cooking classes and community-requested blood pressure kiosk

### Collaboration with 23 researchers on their study challenges, including:

- Cancer-related community-facing studies EFIC Studies
- Studies seeking guidance on underserved population recruitment
- CCHMC adult vaccine studies
- \*Also, CCHMC Biobank, Genomics and EFIC Studies like RPAC

### How We Began: Start-up Steps

- RPAC: 2015; West End C-RAB: 2016
- Steering Committee
- Meet n' Greet presentations
- Flyers, tear pads, targeted potential members
- Potential members interviewed before invitation for demographic representation
- West End C-RAB: election of officers



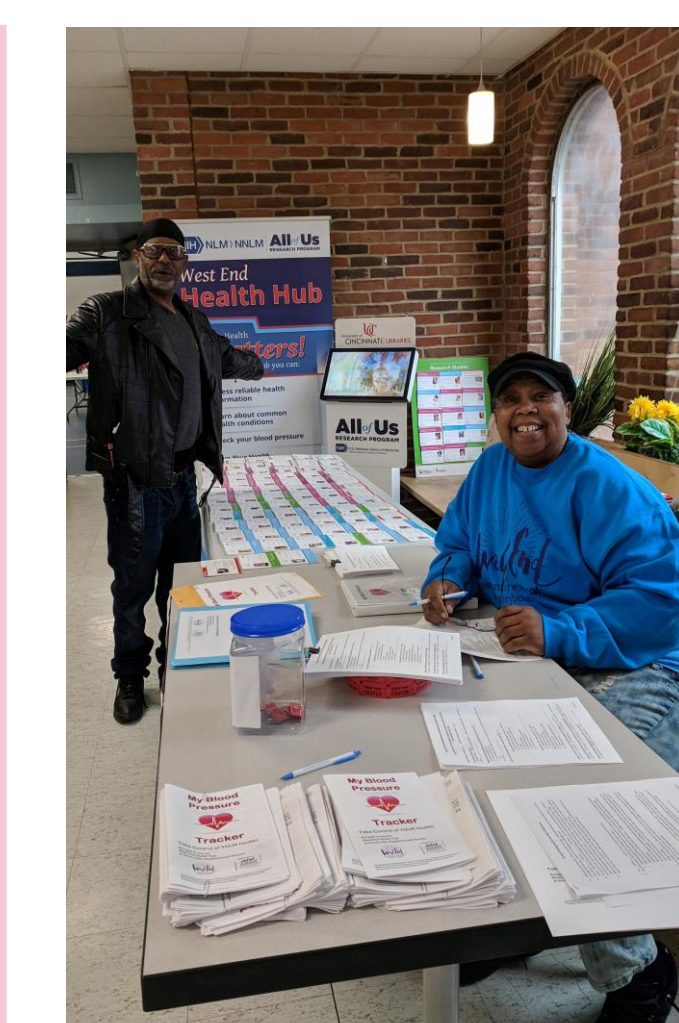
### The Ways We Provide Input: Advisory Group Feedback Methods to Researchers

- Whole- and small-group discussions
- Individual interviews/written evaluations
- Focus groups (with non-member participants)
- Formal feedback to IRB protocols
- Individual advisors on projects/study teams
- Remote/electronic review forms and surveys
- Role-playing scenarios

### The Ways We Grow: Training/Capacity Building

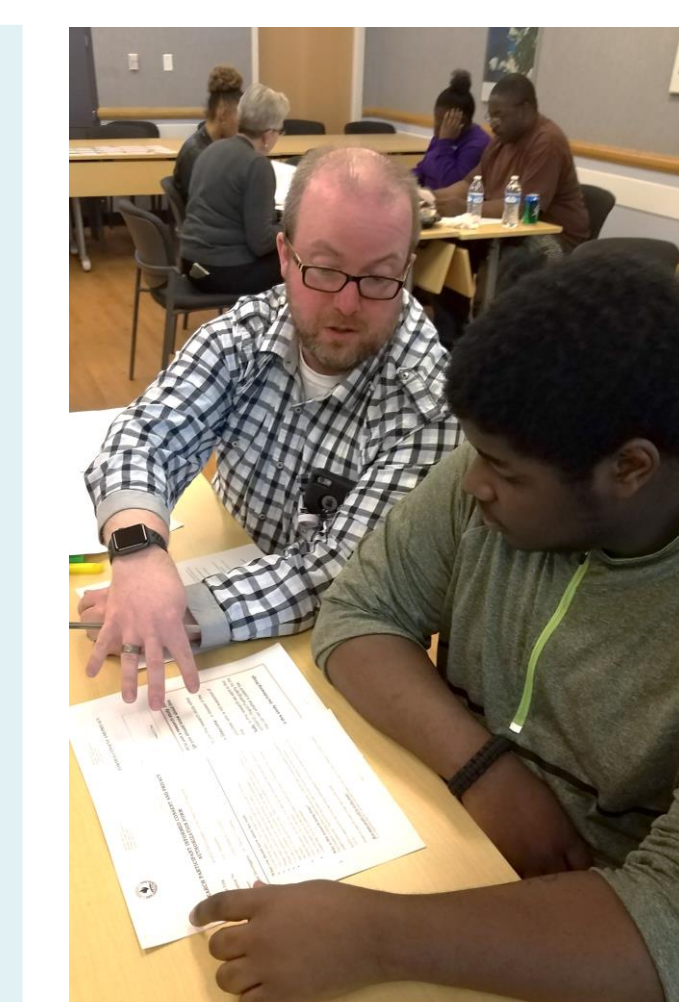
- All members:
- Human Subject Research Ethics Training
  - Field trips to research facilities (CCHMC Biobank)
  - Guest educational speakers

- Also for West End C-RAB members:
- Encourage Community Leaders Institute Training
  - Creation of Community Resource Binder
  - NIH/NIGMS Science Education Program Award (SEPA) partnership



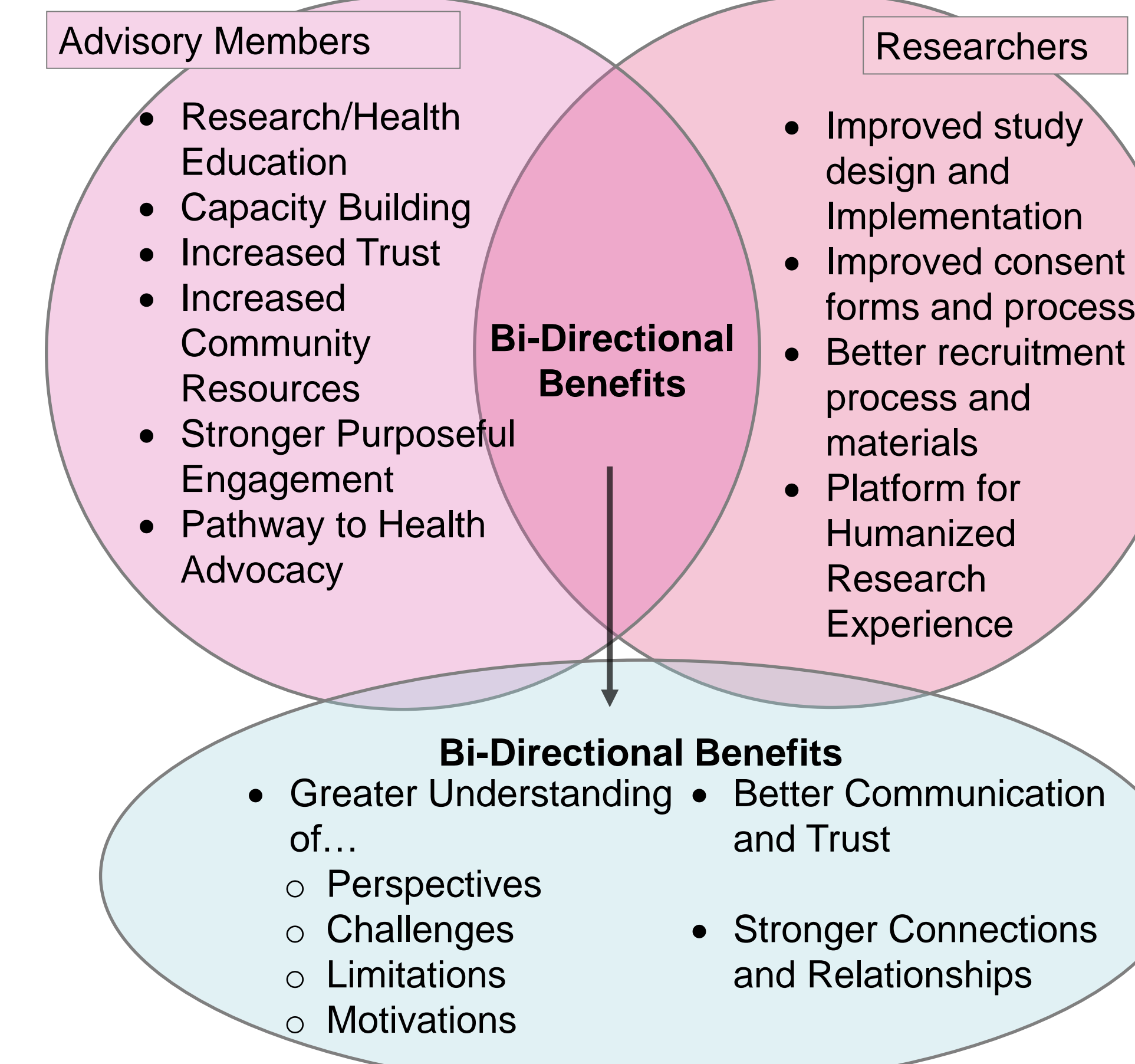
### The Ways We Improve: Evaluation Methods

- Annual assessment surveys or interviews
- Post-meeting assessment member surveys
- Pre-application and post-meeting researcher assessments



## Program Benefits & Outcomes

### Benefits to Advisory Members/Community and Researchers/Studies



### Research "WITH" ...instead of "ON"

- West End Community Benefits**
- Annual Research Health Days -> Bringing together a mix of researchers/studies and community health efforts
  - Community "Walk n' Talks" -> Members providing residents with community-relevant health information and resources
  - Formal MOU's with researchers -> Establishing bi-directional expectations and goals
  - WE C-RAB Members joining research teams and attending CCTST's Community Leaders Institute

### CCHMC Institutional Benefits

- Participant screener in REDCap -> streamlining the screening process for research coordinators
- New CCHMC Informed Consent Template -> providing the participant perspective to identify what should be in the new "Key Information" section
- CCHMC's New Hospital-wide Biobank -> on-going participant/community perspective on creation, design, consenting process, communication, and marketing materials
- WE C-RAB Leadership advising CCHMC Clinical Research Professionals group on health disparities and equity

## Discussion

One notable limitation of the RPAGs is that many researchers across the institutions continue to be unaware of these advisory groups and lack understanding of their value. Their small size could lead to biases. First, RPAC members may not have the experiences to inform the wide range of types of research, therefore regular addition and training of new members is needed. Next, the perspective of C-RAB members from a single community may not be generalizable to other communities, therefore there is value in having multiple C-RABs across a Metropolitan area.

As the two advisory groups evolve, a major opportunity emerging is the chance to broadly market educational understanding of the importance of research and research participation in overall health outcomes and ensuring the engagement with community to better steer this messaging. Working from the existing patient/community relationships will ensure a more authentic, mutually beneficial partnership from the start and overall greater success in implementing research from bench to bedside.