

# Pre-Conference Workshop III (two half-days)

**Date:** Monday, August 24, 2020, and Tuesday, August 25, 2020

**Time:** August 24<sup>th</sup>: 9:00 am – 12:00 pm EST

August 25<sup>th</sup>: 9:00 am – 12:00 pm EST

**Community Partnered Research to Promote Health Equity** (*To register select: Health*)

## Presenters

Anna Ettinger, PhD, MPH, MSW, University of Pittsburgh School of Medicine

Erricka Hager, MPH, University of Pittsburgh Clinical & Translational Science Institute (CTSI)

Felicia Savage-Friedman

Jada Shirriel, MSPPM, Healthy Start of Pittsburgh

Michael Sider-Rose, PhD, Coro Center for Civic Leadership

Marcela Souza

## Purpose of the Workshop and Specific Learning Objectives

Addressing health disparities requires innovative community-based research, prevention, and intervention approaches to build collective strength. This workshop describes a community building approach to reducing disparities in Allegheny County through **The Pittsburgh Study (TPS)**, a longitudinal, community partnered intervention study spanning pregnancy through adolescence that aims to understand and optimize child health and thriving. Through this applied example and a combination of individual and group-based experiential learning methods, this workshop will address several key themes for community partnered research, including building equitable, ethical partnerships with historically disadvantaged communities, strengthening community partnerships through shared decision-making, and co-producing prevention research goals and interventions with communities. The **learning objectives** for workshop participants are to:

1. Describe current frameworks of community engagement focusing on cultural humility and building community assets and collaborations (Session 1).
2. Explain how context powerfully shapes health and how to integrate contextual influences into research (Session 2).
3. Utilize tools to ethically and equitably build research partnerships through leadership and training (Sessions 3-5).
4. Assess current measures of community engagement and develop skills in conducting ethical evaluations of community programs (Session 6).

## Target Workshop Audience

Researchers, practitioners, students, and community members interested in community-based participatory research, prevention, and intervention studies.

### **Materials to be Provided to Attendees**

Each session will build on the activities of the previous sessions to enable participants to consider how to form and engage community partnerships and collaboratives in their own prevention research. The sessions will include activities and handouts/slides related to the skill-building topics presented in each session:

- Session 1: Identifying stakeholders and assessing strengths and needs
- Session 2: Developing cultural humility and understanding context
- Sessions 3 and 4: Building leadership and empowering communities
- Session 5: Developing community partner research training
- Session 6: Measuring and improving community engagement

### **Brief Explanation of Presenters' Qualifications to Conduct Workshop**

Our interdisciplinary team of researchers and community partners collaborating on the Pittsburgh Study have direct experience engaging in large-scale community collaboratives aimed at addressing health equity. Each presenter brings a unique background and skillset to the workshop and has successfully designed and facilitated adult learning activities with diverse audiences.

**Anna Ettinger, PhD, MPH, MSW**, is the Senior Scientist on the Pittsburgh Study, providing oversight on study design, data collection strategies, and coordination across study cohorts and collaboratives. Dr. Ettinger has over 10 years of mixed method (qualitative and quantitative) data collection and analysis, program evaluation, and research experience in maternal and child health, health disparities, mental health, and social determinants of health. Her community-based research with diverse populations includes a qualitative study of low-income inner-city families receiving Supplemental Nutritional Assistance Program (SNAP), concept mapping with diverse neighborhoods in Pittsburgh, as well as work with homeless women with HIV/AIDS and their children. She led a program evaluation of the Office on Women's Health Community Centers of Excellence, integrating qualitative interviews and focus groups with patient surveys and online surveys of community partners. Dr. Ettinger teaches online at the George Washington Milken School of Public Health Department of Prevention and Community Health in the MPH program.

**Erricka Hager, MPH**, is the Community Engagement Coordinator and Special Populations Liaison for the University of Pittsburgh Clinical & Translational Science Institute (CTSI). Ms. Hager has a background in public health ethics and achieving health equity via community engagement, with a focus on social justice. Ms. Hager has four years of experience working with underserved populations and developing supportive and equitable research environments between community members and research partners that allow for inclusion, capacity building, and bidirectional knowledge sharing. Ms. Hager's current role works to improve the health of Pittsburgh residents through the alignment of community, research and training priorities with the goal of quickly assimilating findings from evidence-based research into clinical and community practice. Ms. Hager's research interests include research ethics involving vulnerable populations, social determinants of health, public health ethics, bioethics, and women's health.

**Jada Shirriell, MSPPM**, is the Chief Executive Officer of Healthy Start, a public health organization that focuses on improving maternal and child health and addressing the disparities that lead to infant mortality. Ms. Shirriell is the co-lead of the TPS Healthy Pregnancy Collaborative and is passionate about addressing black maternal health through education,

outreach, research and advocacy. During the current maternal health disparity crisis, Ms. Shirriel has served as a leader educating communities, academics and public policies through participation in anti-racism, equity and health conferences around the country to advocate for measures to address biases and improve health outcomes for those most affected by the disparities.

**Felicia Savage-Friedman**, is the co-director of the Pittsburgh Study. She is also a 500-hour Experienced-Registered Yoga Teacher (E-RYT) and a Yoga Alliance Continuing Education Provider. Felicia has practiced Raja Yoga for 30 years and has taught it for 23 years. Her business, YogaRoots On Location, LLC®, is on a mission to teach and train historically trauma-informed Raja Yoga practitioners by integrating: yoga-based adaptable movements, aromatherapy, Reiki, universal meditation practices, and AntiRacist Raja Yoga Precepts.

**Michael Sider-Rose, PhD**, grew up in Philadelphia, where he had visions of becoming the next Mike Schmidt even though his little-league slugging percentage never reached triple digits. After college, he settled in Pittsburgh for a Ph.D. program in History. Eight years later he emerged from the library with a completed dissertation on religion and politics in post-WWII America. Keen to link the academy and the community, Dr. Sider-Rose took a position with Chicago Semester, an off-campus, experiential learning program. Dr. Sider-Rose worked there from 2000-2006 and enjoyed it so much that he decided to create a similar venture in Pittsburgh. He was Director of Pittsburgh Semester from 2007-2008. In January of 2009, Dr. Sider-Rose joined Coro Pittsburgh, where he now serves as Senior Director of Programs. He designs curricula, develops new programs, trains & facilitates in programs, and spearheads customized projects.

**Marcela Souza**, is the administrative assistant for The Pittsburgh Study, where she extends her advocacy for equity, diversity and inclusion at the workplace. She is also an immigrant from Brazil living in Pittsburgh since 2012, where she became a doula, childbirth educator, and lactation counselor. Marcela has worked with immigrant communities supporting them during pregnancy, childbirth and postpartum. Her project to support families with immigrant backgrounds won the first Women's Health Activist Movement Challenge in Pittsburgh, which reinforced the attention needed to the maternal health inequities in Allegheny County.

## **Outline of Workshop**

**Day 1: Monday, August 24 9AM-12PM**

**9:00-9:45 AM: Session 1. Introduction and Overview to Community Collaborations: The Pittsburgh Study (TPS) Community Engagement Framework (45 minutes)**

**Presenters:** Anna Ettinger and Marcela Souza

**Overview:** This session will provide an introduction and overview of the workshop, including the purpose, learning objectives, and skills that will be gained in each session. This session will then provide a background on community-based participatory research and engagement methods and summarize the team's innovative community engagement framework. We will discuss processes and challenges of setting up a large community-based research study, introduce systems for shared governance and decision-making, and identify strategies to build research reciprocity and create a unified vision for health equity. We will leverage our experience designing and implementing the Pittsburgh Study (TPS) as an example of large-scale community collaboration. With equity, inclusion, and cultural humility as core guiding principles, TPS involves community members as partners throughout all aspects of this research initiative. Community members co-lead TPS Scientific Collaboratives, which are comprised of at least 50% community members who are paid to help design and implement the study. Community partners engaged with the study have committed to help engage diverse communities, collect and share data, and implement interventions.

**Planned Hands-on Activities:** Participants will complete an activity identifying the community partners in their research, assessing current relationships with community stakeholders along the continuum of community engagement, and brainstorming how to engage stakeholders and partners more fully and equitably in their research.

**Skills and Knowledge Gained:**

- Apply community engagement frameworks and strategies
- Describe benefits and challenges of community-based participatory research

**9:45AM – 10:45 AM: Session 2. Impact of Context on Health and Equity: TPS Healthy Pregnancy Collaborative Experience (1 hour)**

**Presenters:** Jada Shirriell and Erricka Hager

**Overview:** This session will describe the profound effects contextual and neighborhood factors have on health risks, opportunities, behaviors, and outcomes as well as strategies for integrating these considerations into community partnered prevention research. Maternal and child health, for example, is characterized by persistent disparities in outcomes based on structural, contextual, and social forces including race/ethnicity, neighborhood access, and income. In Pittsburgh and Allegheny County, Black maternal and infant mortality is significantly higher than white and other racial/ethnic groups. The overall infant mortality rate in Allegheny County is 6.0 per 1,000 live births, while the rate for Black infants is 4.5 times higher than that of white infants (14.1 deaths per 1,000 live births compared to 3.3 deaths per 1,000 live births).<sup>1</sup> Differences are starker by neighborhood, with infant mortality rates exceeding 20 deaths per 1,000 live births in 4 neighborhoods from 2011-2016.

Promoting healthy pregnancy, births, and optimal development during infancy and early childhood requires preventing and addressing contextual and neighborhood-level precursors of maternal and infant mortality and morbidity. Using a cultural humility lens, TPS developed the Healthy Pregnancy Collaborative focused on the needs of pregnant women and newborns. The team conducted community engagement and outreach in neighborhoods at high risk for preterm birth, provided orientation and training for community partners, and engaged community members in designing appropriate prevention-based interventions to improve pregnancy and birth outcomes.

**Planned Hands-on Activities:**

Participants will complete an assessment of cultural humility to build self-awareness of their beliefs and implicit biases. Participants will identify how contextual factors and social determinants of health influence their community partners. Participants will continue working in their toolkit to discuss strengthening community partnerships, including time and budget considerations for community partners in the implementation of their research activities.

**Skills and Knowledge Gained:**

- Recognize the difference between cultural humility and cultural competency
- Integrate the influence of contextual, neighborhood, and social determinants of health in prevention work

**10:45 AM-11:00 AM: Break (15 minutes)**

**11:00AM -12:00PM: Session 3. Building Community Leadership, Trust, and Ownership (1 hour)**

**Presenters:** Michael Sider-Rose

**Overview:** This session will provide an introduction to leadership development in local communities. It will draw on two frameworks: Trauma Informed Community Development (as developed by the Neighborhood Resilience Project<sup>2</sup>) and Adaptive Leadership. The goal of the leadership development training is to engage university researchers and community residents to develop a mutually beneficial partnership. The work of community leadership is designed to be embedded in the Pittsburgh Study's strategy to build a certificate training program to empower community partners. The multi-disciplinary leadership and capacity building program will provide a forum for community and university partners to build skills and experience in a variety of areas including:

- Leadership training
- Advocacy skills training
- Data and research literacy
- Research coordination (engagement, operations, ethics)
- Resource navigator for local community resources

**Planned Hands-on Activities:**

Participants will practice distinguishing between adaptive and technical components of challenges and then apply this knowledge to concrete situations they are facing with community partners.

**Skills and Knowledge Gained:**

- Understand Trauma-Informed Community Development and Adaptive Leadership
- Apply strategies to build community leadership skills

**Day 2: Tuesday, August 25 9AM-12PM**

**9AM-10AM: Session 4: Building Ethical, Equitable Partnerships Part 1: On the Path of Humanizing Institutional Processes (1 hour)**

**Presenters:** Marcela Anita Souza and Felicia Savage Friedman

**Overview:** Our work is to power-up community members. One of the greatest challenges for promoting equity and social justice is to question the long ago established procedures and flowcharts within administrative functions that present a real barrier to community members feeling valued by institutions and systems. Humanizing institutional processes requires questioning everything that is categorized as "standard procedure" which shelters institutional discrimination. This workshop will discuss forms of systemic discrimination that dehumanize community members attempting to work with institutions through standard procedures. It will also share some of the strategies that the Pittsburgh Study adopted to address inherited institutional discrimination and ensure equitable community participation from collective development of shared-values all the way through recognizing community members time as a valued asset.

**Planned Hands-on Activities:** Participants will be encouraged to think about their own environments and identify forms of oppressions, power dynamics, and how workers systematically reproduce them. Anonymous reflections on participant's experience with oppressions at the workplace will be collected and share through polls.

**Skills and Knowledge Gained:**

- Identify standard procedures that configures institutional discrimination and dehumanizes community members
- Develop a plan for mitigation and humanization of institutions

**10:00AM -11:00 AM: Session 5. Building Ethical, Equitable Partnerships Part 2: Engaging Community Members in Research Training (1 hour)**

**Presenter:** Erricka Hager

**Overview:** One strategy to build equitable community partnerships and increase community receptivity for research is the development of a tailored research training programs designed for academic researchers and their community partners. The Community PARTners Core (CPC) of the University of Pittsburgh Clinical & Translational Sciences Institute facilitates relationships between community organizations and researchers to enhance partnered research. The CPC, in partnership with University of Pittsburgh Institutional Review Board (IRB), the Community Research Advisory Board, and community partners, have developed a research ethics training.<sup>3</sup> This session will describe the IRB-approved Community Partnered Research Ethics Training and Certification (CPRET) program. CPRET is intended to promote bidirectional learning and makes space for community partners and academic researchers to engage more deeply and equitably together in the research process. Each training is adaptable to the specific needs of the research study and community partners. Traditional research ethics trainings generally require high literacy levels and access to technology, fail to discuss the barriers to participation, seldom include examples of unethical research, and do not incorporate community lived experiences. CPRET was informed by and piloted with community members to be an effective and meaningful training program. It is designed to: (1) holistically promote intersectionality of identities, intercultural competence, and awareness of core human subjects research ethics principles, (2) cultivate community capacity to participate in community-based and community partnered research, and (3) assist with the integration of community and stakeholder input to the design, development, implementation, evaluation research.

**Planned Hands-on Activities:**

Workshop participants will practice and reinforce the CPRET principles.

**Skills and Knowledge Gained:**

By participating in a mock research ethics training, attendees will be able to:

1. Discuss the development and piloting of this Community Partnered Research Ethics Training and Certification.
2. Describe outcomes and lessons learned from academic and community partners who have participated in this Community Partnered Research Ethics Training and Certification.
3. Explain how to adapt an ethics training module to a specific research project.

**11:00-11:15AM: Break (15 minutes)**

**11:15-12:00 PM Session 6. Conducting Ethical Evaluations of Community Prevention Programs: Measuring Community Engagement and Workshop Wrap-up (1 hour)**

**Presenter:** Anna Ettinger and all presenters for wrap-up

**Overview:** This session will provide an overview of available measures and strategies for assessing community engagement, trust in research, and achievement of study principles of equity and inclusion. Incorporating community feedback into all steps of the research process is critical to ensuring that community members feel their contributions are valued; that research partnerships are sustainable; and that research processes have been designed equitably to promote community benefit and social justice. Currently, validated measures of community engagement and research reciprocity are limited, although recent efforts to develop them with community input have been promising.<sup>4,5</sup> The TPS team developed an assessment based on their shared principles to assess community engagement and implemented ongoing assessments of community perceptions about their opportunities to contribute and lead aspects

of the study. The session will also discuss other ethical issues related to community partnered research, including co-authorship, data privacy and accessibility, and involvement of groups experiencing concentrated disadvantage.

This session will conclude with a summary of the workshop, including a synthesis of major points and key themes in community partnered research discussed during each session. Participants will have the opportunity ask questions and discuss any questions or challenges they have with all the presenters.

**Planned Hands-on Activities:**

Participants will complete an online community engagement measure and identify ways they would utilize or adapt the measure to their research. Through critical thinking and application of knowledge from all of the sessions, they will develop an action plan to leverage the principles and strategies presented throughout the workshop into their own prevention research.

**Skills and Knowledge Gained:**

- Analyze community engagement measures and strategies
- Identify ethical challenges and potential solutions for community partnered research

**Relevance to Conference Themes and Training Needs Assessment Task Force (TNATF)-identified Themes**

This workshop is aligned with several of the SPR conference themes and TNAFT-identified themes, as well as additional areas identified by the SPR as training needs and priorities. The overarching conference themes of **place-based prevention** and **increasing health equity and strengthening resilience** are central to the entire workshop through its discussion of The Pittsburgh Study, aimed at increasing child thriving in Pittsburgh and addressing health inequities through community partnered research. Workshop Session 1 focuses on TNATF theme 3, **developing cultural competency and community collaborations**, by describing processes for approaching health disparities through cultural humility. Workshop Session 2 focuses on TNATF theme 1, **understanding the role of context in shaping health behavior**, using the neighborhoods of Pittsburgh and experiences of racial and gender inequities as a case study. Workshop Sessions 3-5 focus on **Building equitable and ethical community partnerships**, by training community partners as researchers, leaders, and community advocates and providing skills and experience they can transfer to their community. Finally, Workshop Session 6 describes **how to ethically conduct evaluations in prevention programs in the community**.

**References**

<sup>1</sup> Allegheny County Health Department. (2016). Allegheny County Mortality Report: 2016. Retrieved October 19, 2019 from: [https://alleghenycounty.us/uploadedFiles/Allegheny\\_Home/Health\\_Department/Resources/Data\\_and\\_Reporting/Chronic\\_Disease\\_Epidemiology/2016-Final-Mortality-Report.pdf](https://alleghenycounty.us/uploadedFiles/Allegheny_Home/Health_Department/Resources/Data_and_Reporting/Chronic_Disease_Epidemiology/2016-Final-Mortality-Report.pdf).

<sup>2</sup> Neighborhood Resilience Project (2019). Retrieved October 30, 2019 from <https://neighborhoodresilience.org/>

<sup>3</sup> Yonas, MA. Et al. (2016). Community partnered research ethics training in practice – A collaborative approach to certification. *J Empir Res Hum Res Ethics*, 11(2), 97-115.

<sup>4</sup> Goodman, M.S., Ackermann, N. Bowen, D.J., & Thompson, V. (2019). Content validation of a quantitative stakeholder engagement measure. *J Community Psychology*, 47, 1937-1951.

<sup>5</sup> Hamilton, C.B. et al. (2018). Development and pre-testing of the Patient Engagement in Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. *PLoS One*, 13(11), e0206588.