TRANSFORMING COMMUNITY-LED HEALTH RESEARCH SYMPOSIUM

Table of Contents

Resources for Engaging in Community-Led Health Research

Principles of Community Engagement

Articles and Papers

- [CDC Guide: What Is Community Engagement?](#)
- [National Equity Project: The Lens of Systemic Oppression](#)
- [CCPH Principles of Partnership](#)
- [CDC/ATSDR: Principles of Community Engagement](#)

Community-Based Participatory Research

- [Tufts CTSI Community and Stakeholder Engagement](#)
- [Community Strategies for Culturally Responsive Research](#)
- [Progress in Community Health Partnerships: Research, Education, and Action](#)
- [Center for Community Health and Development: Community Tool Box](#)
- [Chicago Beyond: Why Am I Always Being Researched](#)
- [Research Across the Walls: A Guide to Participatory Research Projects & Partnerships to Free Criminalized Survivors (Survived and Punished)](#)
- [Decolonizing Community-Based Research](#)
- [Research Justice Worksheet](#)
- [Promising Practices Guide for community-based participatory research](#)
- [Facilitators and barriers to community-led monitoring of health programs: Qualitative evidence from the global implementation landscape](#)
- [The Power of Community-Generated Research in our Work for Justice](#)
- [2022 Survey: A Focus on Racial Equity](#)

History of North Carolina

Articles and Papers

- [History of the Immigrant & Refugee Rights Project](#)
- [Carolina Demography](#)
- [North Carolina History Project](#)
- [About the NC History Digital Textbook](#)

- [Wyatt Outlaw and the white men who put a monument where they lynched him](#)
- [North Carolina Fast Facts and Timelines](#)
- [Economy of North Carolina](#)
- [Robeson County, NC](#)
- [Public Schools of Robeson County](#)
- [2021 Forsyth County Community Health Assessment (CHA) Report](#)

Panel Discussion

- [History Hour: Refugees and Resettlement in WNC, a panel discussion](#)

Overcoming Systems of Oppression in Research

Articles and Papers

- [Beyond Systems of Oppression: The Syndemic Affecting Black Youth in the US](#)
- [Improving Health Equity: Eliminate Racism and Other Forms of Oppression](#)
- [Intersectionality as Critical Social Theory](#)

Bias in Philanthropic Funding

- [Overcoming the Racial Bias in Philanthropic Funding](#)
- [No Strings Attached: Philanthropy, Race, and Donor Control From Black Power to Black Lives Matter](#)
- [The 6 Grantmaking Practices of Trust-Based Philanthropy](#)

Videos

- [Black Storytelling from Margin to Center](#)
- [Study Reveals Black Americans as Hidden Native Original People](#)
- [Research Justice: Decolonizing Knowledge, Building Power](#)
- [Fitting in the Food System](#)
- [Creative Aging Network of NC](#)
- [Social Identities and Systems of Oppression: How to understand power](#)

Barriers and Lessons Learned in Community-Led Research

Articles and Papers

- [Barriers And Facilitators To Community-Based Participatory Mental Health Care Research For Racial And Ethnic Minorities](#)
- [Relational community engagement within health interventions at varied outcome scales](#)
- [IIED Resource](#)
- [Community Partner Perspectives on Benefits, Challenges, Facilitating Factors, and Lessons Learned from Community-Based Participatory Research Partnerships in Detroit](#)
- [Studying Breast Cancer Risk in Asian American Communities with Dr. Scarlett Gomez](#)
- [Improving Health Equity: Eliminate Racism and Other Forms of Oppression](#)

Webinar

- [ASHE CIHE March 2022 Research Webinar](#)

Practitioner and Researcher Positionality

Articles and Papers

- [To Hell with Good Intentions by Ivan Illich](#)
- [Positionality Statements as a Function of Coloniality: Interrogating Reflexive Methodologies](#)
- [R-Words: Refusing Research](#)

Diverse Ways of Knowing

Articles and Papers
- [What healing looks like for Asian American Communities](#)
- [Rap Music](#)
- [Britannica on Hip-Hop](#)
- [Read Poetry on Spoken Word](#)
- [Ways of Knowing: The Diversity of Knowledge](#)

Websites
- [NCSU Therapeutic Horticulture](#)
- [Facebook Page - Robeson County Community Bi-Lingual Teaching Garden](#)
- [The Conservation Fund: Resourceful Communities](#)
- [Center for Justice Innovation](#)

- [Interdisciplinary Research Leaders](#)
- [See Your Words](#)
- [Thriving Together](#)

Organizations and Initiatives
- [NCSU Therapeutic Horticulture](#)
- [Facebook Page - Robeson County Community Bi-Lingual Teaching Garden](#)
- [The Conservation Fund: Resourceful Communities](#)
- [Center for Justice Innovation](#)
- [Interdisciplinary Research Leaders](#)

Research Tools and Frameworks
- [Community-Based Systems Dynamics](#)
- [Ageing among Black and non-Hispanic White older adults: A community-based system dynamics approach to examining quality of life](#)
- [ABLe Change Process: Tools and Resources for Community Systems Change](#)
- [Able Pocket Guide for Community Systems Change](#)
- [Trial Innovation Network Toolkit](#)
- [A Toolkit for Centering Racial Equity Throughout Data Integration](#)
- [Research Tools for Organizers Training Series (Map the Power)](#)
- [Community-Centered Dissemination Toolkit](#)
- [The Community-Engaged Research Framework](#)

Community Initiatives and Reports
- [Full Frame Initiative - Community Bill of Rights](#)
- [Shifting the Power Balance: Creating Health System Accountability through Trusted Community Partnerships](#)
- [How Racism Can Affect Child Development](#)
- [Do No Harm Guide: Applying Equity Awareness in Data Visualization](#)
- [Sabbaticals for BIPOC Leaders](#)
- [A Growing Movement of Sabbaticals for BIPOC Leaders](#)
- [BIPOC ED Coalition Launches Sabbatical Program, Prioritizing Well-Being Of Black, Indigenous And People Of Color Nonprofit Leaders](#)
- [BIPOC ED Coalition Grants $1.37M to Nonprofit Leaders for Sabbaticals and Respites](#)
- [Update: 246 Cities, Counties, Leaders Declare Racism a Public Health Crisis!](#)

Books
- [The Art of Community by Charles H. Vogl](#)
- [Decolonizing Methodologies: Research and Indigenous Peoples by Linda Tuhiwai Smith](#)
- [Research as Resistance: Revisiting Critical, Indigenous, and Anti-oppressive Approaches by Leslie Brown, Susan Strega](#)
- [Influencing Social Policy: Applied Psychology Serving the Public Interest](#)
- [Organize! Building from the Local for Global Justice by Aziz Choudry, Jill Hanley & Eric Shragge](#)
- [Thicker Than Blood: How Racial Statistics Lie by Tukufu Zuberi](#)
- [Essentials of Critical Participatory Action Research by Michelle Fine, María Elena Torre](#)
- [Black Feminism in Qualitative Inquiry A Mosaic for Writing Our Daughter's Body By Venus E. Evans-Winters](#)

Barriers to Practicing Community-led Health Research

Below are the key themes and barriers to community-led health research participants identified:

Structural Barriers

- System designed to extract means of production from communities, limiting their ability to live a healthy life
- Institutional policies that hinder applying resources to community needs
- Lack of validation in academic spaces, which can have a chilling effect on pre-tenure scholars
- Lack of understanding and recognition of Indigenous knowledges, cultures, and traditional medicines
- Lack of resources and stable funding for community-based organizations
- Competitive funding models and insufficient funding for long-term sustainability

Cultural and Linguistic Barriers

- Cultural and linguistic barriers prevent marginalized populations from participating in community-based participatory research (CBPR)

- Language and cultural barriers in working with Latino and African American families in predominantly white/native communities
- Racism in the medical field, education, and justice system faced by African Americans
- Misunderstandings and miscommunications due to lack of cultural competence and understanding of community contexts

Organizational Barriers

- Obstacles in accessing resources and performing research to mitigate social challenges
- Time constraints, lack of communication, and financial struggles
- Psychological barriers, objections, and reactions in incorporating social justice, anti-racism, cultural competence, and reflection in engagement practices
- Fear of internal or public criticism and controversy in poorly executed community engagement projects
- Bureaucratic processes and administrative burdens delaying or hindering project implementation

Power Dynamics and Institutional Constraints

- Power imbalances between academic researchers and community members hinder genuine partnership
- Institutional constraints and policies that do not support community-led research approaches
- Academic reward structure focused on grant funding and high-impact journal publications, undervaluing community engagement and dissemination of research findings
- Ethical guidelines (IRB restrictions) that do not align with community needs, often protecting institutions over people
- Disconnect between community-led initiatives and academic or institutional priorities

Trust and Relationship Building

- Structural barriers such as systemic racism and discrimination create an environment of mistrust between researchers and community members
- Lack of cultural competence and understanding of the cultural contexts of communities can lead to misunderstandings and miscommunications

- Historical and ongoing inequities leading to a lack of trust between researchers and communities
- Need for genuine, reciprocal relationships beyond formal agreements

Long-term Commitment and Sustainability

- Long-term commitment beyond funded grant projects and the need for resources to sustain partnerships
- Focus on short-term returns on investment and lack of value attributed to community-led research
- Insufficient funding, lack of resources, and opportunities for growth and mentorship
- Financial difficulties impacting the ability to participate in research
- Individual needs conflicting with principles of partnership, such as the need for income affecting the flow of resources to the community

Knowledge and Information Barrier

- Lack of access to information, resources, and authentic research
- Lack of understanding, awareness, and trust in community insights and Indigenous knowledge
- Lack of language and communication that resonates with the scientific community and validation in academic spaces
- Community insights often dismissed as anecdotal or less-than evidence

Barriers to Practicing Community-Led Health Research

- Lack of funding, recognition, and support for community partnerships
- Unwillingness to invest in partnerships that address root causes, focusing more on short-term program-based solutions
- Bias, systemic racism, lack of accountability, security, and privilege mentalities
- Need for unlearning traditional research approaches and overcoming biases in predominantly white institutions

Barriers to Applying Principles of Community-Led Health Research

- Complexity and underestimation of applying principles, especially by those lacking respect and expertise in community-led research
- Lack of passion, commitment, and humility to honor the expertise of the partnership and community members

- Racism, lack of resources, and ongoing adversities that impede progress and improvement
- Lack of training and support for both academic researchers and community members

Additional Barriers

- Lack of sincerity, mutual respect, and humility in partnerships
- Lack of flexibility and dedicated time for community partnerships and research
- Lack of accountability measures to address biases and systemic racism
- Lack of dissemination of research findings directly to the community and establishing trusting relationships

Community-Led Health Research Project Examples

- [The Montagnard Hypertension Project](#)
- [Detroit Urban Research Center (Detroit URC)](#)
- [Pride Center San Antonio](#)
- [Oklahoma State University](#)
- [Queens Village Cincinnati](#)
- [Community Action to Promote Healthy Environments (CAPHE)](#)
- [Báa nnilah (Apsáalooke Nation/Crow)](#)
- [ACT Cincy](#)
- [Midwest Collaborative for Women's Health (MCWI)](#)
- [Indigenous Early Learning Collaborative](#):
- [BIPOC-to-BIPOC Initiative](#)
- [West Atlanta Watershed Alliance](#)
- [Philly Thrive](#)
- [No Cop Academy](#)
- [Courtwatch DC](#)
- [Mapping Community Ecosystems of Collective Care](#)
- [Pitt County All-Stars 4-H Club](#)
- [Farmworker Association of Florida](#)
- [LEAP Health and Wellness Collaboration](#)
- [Asian Health Coalition](#)
- [Asian Women for Health](#)
- [Asian Media Access](#)
- [TikTok Cultures](#)