



Sustaining Community Engagement in Genomics Research: A
Workshop

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Sustaining Community Engagement in Genomics Research: A Workshop

Board on Health Sciences Policy Roundtable on Genomics and Precision Health

Integrity

Service

Justice

Wisdom

Innovation

Excellence

Disclosure Statement

I have no relevant personal/professional/financial relationship(s) with respect to this educational activity

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Institutional Context

Morehouse School of Medicine Mission Statement

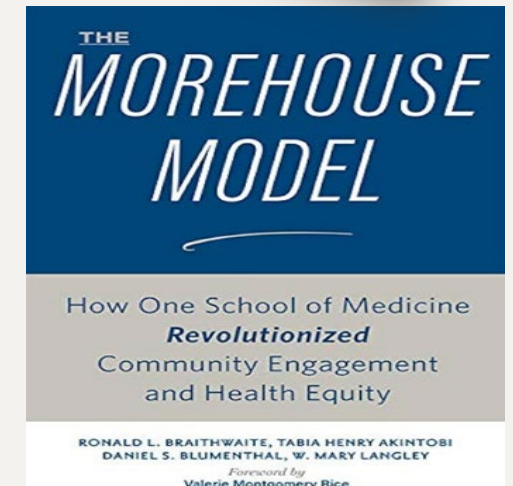
We exist to:

- Improve the health and well-being of individuals and communities
- Increase the diversity of the health professional and scientific workforce
- Address primary health care through programs in education, research, and service

With emphasis on people of color and the underserved urban and rural populations in Georgia, the nation, and the world.

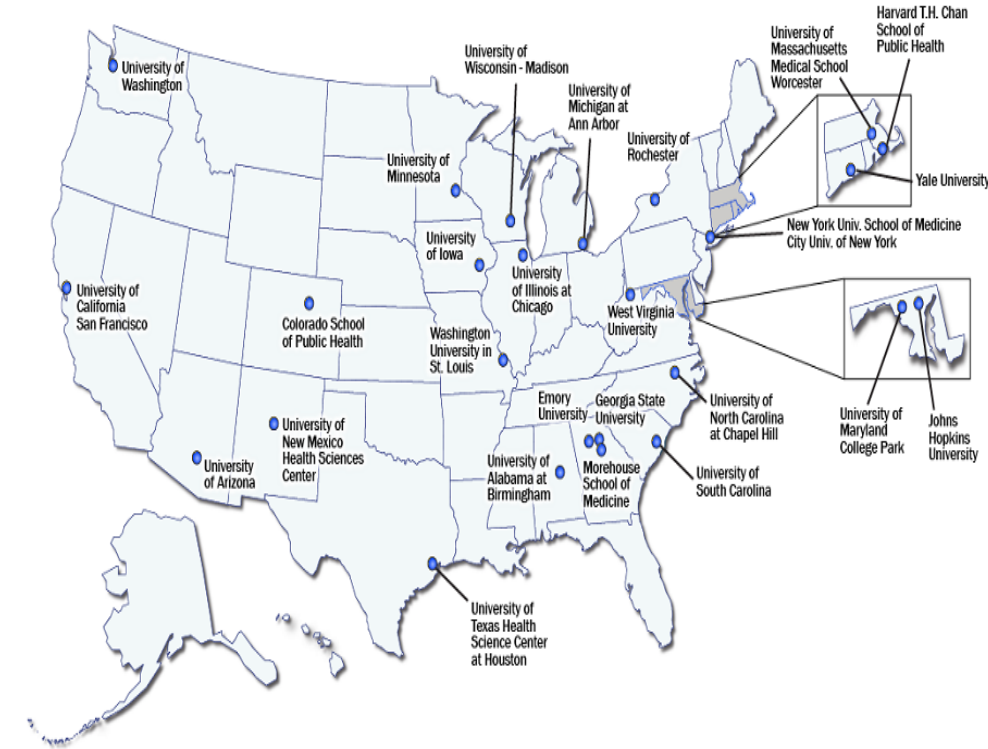
We Need:

- Compassionate Care
- Innovative Medicine
- Culturally Competent and sensitive care
- Service to the Underserved
- Primary Care Professionals
- **COMMUNITY ENGAGED learners, researchers, clinicians and practitioners**



The Prevention Research Center (PRC) Program

- Centers develop, test, and evaluate solutions to public health problems
- Each PRC is funded for 5 years to maintain a research center and conduct prevention research that promotes health and prevents chronic illness and other diseases and disabilities
- The solutions developed intended to be applied widely, especially in populations affected by health disparities



Infrastructure: Community Governance

MSM Prevention Research Center Community Coalition Board:

Local History, National and Global Reach

Demonstrate the value of community governance (vs. advisory) boards

- **Composition**

- Community Residents (majority in #, all leadership seats, weighted votes)
- Academic Institution Representatives
- Agencies

- **Function**

- Policy-making body
- Identifies health priorities and approves projects
- Sets policies and oversees research infrastructure & operations
- Provides information on research activities to organizations and agencies
- Ensures clear benefits of community-engaged research
- Establishes or sustains trust with community

The community engagement course and action network: strengthening community and academic research partnerships to advance health equity

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Background: Historically Black Colleges and Universities and Minority Serving Institutions are uniquely positioned to implement community-campus research partnerships based on a history of service, the pursuit of community trustworthiness and student demographics often similar to surrounding marginalized communities. The Morehouse School of Medicine Prevention Research Center collaborates with members of Historically Black Colleges and Universities, Minority Serving Institutions, and community organizations on the Community Engaged Course and Action Network. This network is the first of its kind and aims to strengthen members' ability to implement Community-Based Participatory Research (CBPR) principles and partnerships. Projects address public health priorities including mental health among communities of color, zoonotic disease prevention, and urban food deserts.

Materials and methods: To assess the effectiveness of the network, a Participatory Evaluation framework was implemented to conduct process evaluation which included review of partnership structures, operations, project implementation processes, and preliminary outcomes of the research collaborations. A focus group of Community Engagement Course and Action Network members (community and academic) was also conducted to identify benefits and challenges of the network with emphasis on key areas for improvement to further enhance the relationships between partners and to facilitate their subsequent community-campus research.

Results: Network improvements were tied to themes strengthening community-academic partnerships including sharing and fellowship, coalition building and collaboration, and greater connections and awareness of community needs through their current community-academic partnerships. The need to conduct ongoing evaluation during and after implementation, for determining the early adoption of CBPR approaches was also identified.

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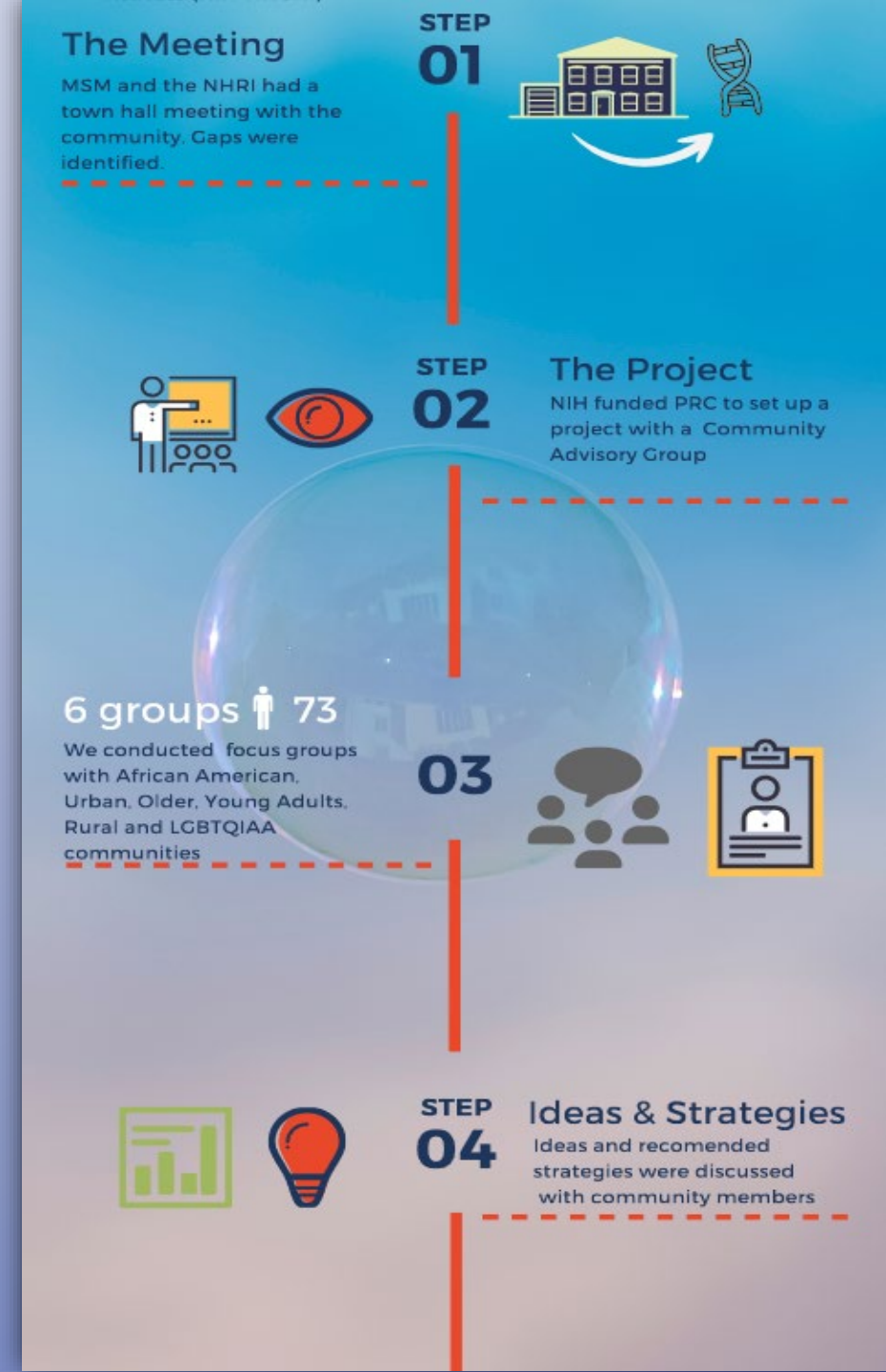


Introduction

The purpose of **the NHGRI-Morehouse School of Medicine partnership** was to understand the **current knowledge, attitudes, perceptions, barriers, facilitators and recommendations** related to effective community engagement in human genome research. The results will be translated to a toolkit for researchers, by community

Methods

- **Six focus groups** (N=73) were conducted (March 2020-May 2020) among segmented groups [**rural, urban, younger (18-34), older (> 65) and LGBTQIAA**].
- Recorded discussions were transcribed and initial themes identified
- **Community data interpretation** took place over eight meetings with the local community advisory board and NHGRI community advisory representatives (August 2020-January 2021)



Results

Addressing Benefits/Risks

“How will it benefit me...and the community? It ain’t just bout me. It’s about all of us” - Older adults

“...the **stigma** that exists that anything that is going to involve blood or going to reveal one’s [HIV] status I think would be something that **some would be leery of**. Not every one’s completely comfortable with **people knowing** their HIV status, and that might be a **deterrent** for the males and for women as well” - LGBTQIAA

Research outcomes that are child- and family-centered

“The whole idea of a person trying to do research is to be able to **help** themselves **better their health** and better **pass it down to their children** so that they can know what to look forward to.” - African Americans

“I think it would be an advantage is knowing...**what’s going on in your family’s history** or just what’s going on with your body as well just having that information” - Young adults

Calling out concerns and answers regarding data use

“I don’t want, you know, them to **keep my DNA** and do **whatever they please** with it and feel like that’s okay. So, that’s definitely my biggest fear and concern.” - Young adults

“just a general **skepticism** that **your genes are going to be used for truly what the test says** and that you’ll be compensated if you need to be a higher test subject how these things are proven in history.” – Urban adults

Results (continued)

Information and ownership

“I think it’s very important that if you **take the knowledge** of anybody, **it’s a value to them**. You know if I wrote a book and you copyrighted that book, then **I have value in what you sell**. It’s still in the movie industry, so I think eventually the people that are doing these tests, these research and different stuff, they need to **pay for our value** that’s in there because if they’re going to research it, they’re going to get a big grant from whatever pharmaceutical company and once everybody gets rich and we still sitting where we were.” – Older adults

“So, a **sense of ownership** surrounding the **research** or the study that’s being done. That will also allow people to be more encouraged or excited or willing to **participate**.” – Young adults

Guidance regarding people trusted as research messengers/influencers

“I feel strongly when people come to get information from communities, they don’t **build the relationships**—strong relationships, and that’s why people don’t participate because they don’t trust.” – African Americans

“I think being **familiar** with the person who’s collecting the data—having someone in the community **so you feel comfortable with that person** as opposed to someone coming from outside of the community and not being able to relate to that person. That would make it **more attractive** and I think it would gain more participation.” – LGBTQIAA

BOARD EVALUATION AND CONTINUOUS IMPROVEMENT-THE PRC CCB SATISFACTION SURVEY

- Created in 2010 by the Data Monitoring and Evaluation Committee
- Developed to ensure accountability of Community Coalition Board (CCB) research priorities and activities
- Purpose of Assessment
 - Allows CCB to provide feedback anonymously
 - Coalition building
 - To prevent “Mission Drift”

BOARD EVALUATION AND CONTINUOUS IMPROVEMENT- THE PRC CCB SATISFACTION SURVEY DEVELOPMENT OF THE TOOL

- Four Major Areas
 - Satisfaction
 - Leadership
 - Involvement
 - Communications

SATISFACTION

- | | |
|---|---|
| 1 | Clarity of the vision for where the CCB is going |
| 2 | Follow through on The CCB's activities |
| 3 | Planning process used to prepare the CCB's objectives |
| 4 | Efforts to promote collaborative action with MSM PRC staff/faculty |
| 5 | Training and technical assistance provided by MSM PRC staff/faculty |
| 6 | Training and technical assistance provided by CCB members |

LEADERSHIP

- 1 Commitment of The CCB to build and sustain a diverse membership
- 2 Collaboration between CCB leadership and members
- 3 CCB leadership's active engagement of CCB members
- 4 Opportunities for CCB members to take leadership roles in CCB initiatives
- 5 Collaboration between MSM PRC staff/faculty and CCB members
- 6 Opportunities for CCB members to take leadership roles in PRC initiatives

Measure What Matters

- CONTEXTS
- PARTNERSHIP PROCESSES
- INTERVENTION AND RESEARCH
- OUTCOMES
- **Diversity, Equity and Intersectionality**



Source: Oetzel, J., Wallerstein, N., Duran, B., Sanchez-Youngman, S. Nguyen, T., Woo, K. Wang, J. Schulz, A., Kaholokula, J., Israel, B., & Alegria, M. (2018). Impact of Participatory Health Research: A Test of the Community-Based Participatory Research Conceptual Model. BioMed Research International. 2018. 10.1155/2018/7281405.

Measure What Matters

- Policy Environment: University and Community Changes
- Sustainable Partnerships and Projects
- Empowerment
- Shared Power Relations in Research/Knowledge Democracy
- Cultural Reinforcement/Revitalization
- Growth in Individual Partner & Agency Capacities
- Research Productivity: Research Outcomes, Papers, Grant Applications and Awards
- Community/Social Transformation: Policies and Conditions
- Improved Health/Health Equity



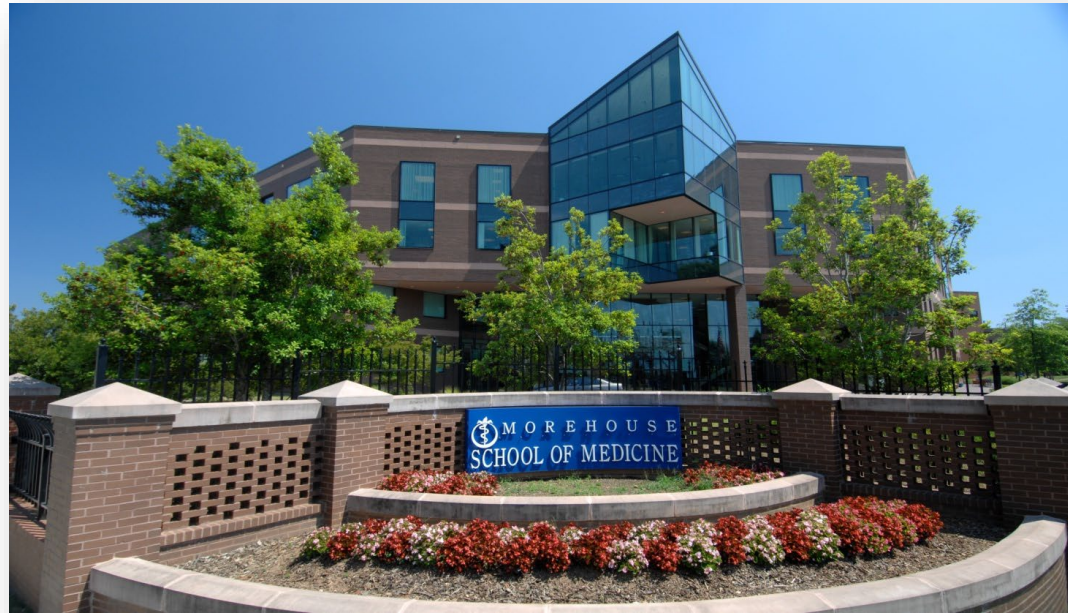
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How Do You Innovate and Lead?

- Assume and Embrace the Complexities of Intersectionality
- Challenge Team and Practice Science Boundaries
- Make Room for Essential *Co-Creators and Translators*: Community and Patient Leaders
- Invest Resources/Time to Foster and Sustain Trustworthiness
- Challenge Existing Diversity, Equity and Inclusion Motives, Optics and Initiatives



Contact Information



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