



## Health Disparities and Community-Based Participatory Research

Introduction to Principles and Practice of Clinical Research

Tiffany M. Powell-Wiley MD, MPH  
Assistant Clinical Investigator

Social Determinants of Obesity and Cardiovascular Risk  
Cardiovascular and Pulmonary Branch  
Division of Intramural Research  
National Heart, Lung, and Blood Institute  
[tiffany.powell@nih.gov](mailto:tiffany.powell@nih.gov)

 March 28, 2016 

---

---

---

---

---


---

---

---

### Objectives

- Introduction to CBPR
- Role of CBPR in reduction of health disparities
- Case Study:
  - CBPR work by Powell-Wiley Research Group
  - The Washington D.C. Cardiovascular Health and Needs Assessment



---

---

---

---

---

---

---

---

### Types of Community Engagement

- Practice-based Research Networks (PBRN)
- Community-oriented Primary Care (COPC)
- Community-based Participatory Research (CBPR)



---

---

---

---

---

---

---

---

**Definition of Community-Based Participatory Research**

- A partnership approach to research
- Equitably involves community members, organizations, and academic researchers in all aspects of the research process
- Enables all partners to contribute
- Enhances a common understanding
- Integrates knowledge gained with interventions and policy change

Israel, B.A., Schulz, A.J., Parker, E.A. and Becker, A.B, 1998 

---

---

---

---

---

---

---

---

**Definitions of Community**

- Populations defined by geography, race/ethnicity, gender, sexual orientation, disability, or health condition
- Groups with common interest or cause
  - Healthcare or service agencies/organizations
  - Healthcare or public health providers
  - Community-based groups with public health concerns
- State, local, and tribal leaders and policy-makers



---

---

---

---

---


---

---

---

**What is the rationale for CBPR?**

- Increasing demands for community-driven research
- Understanding of importance of local and cultural context/external validity
- Complex health and social problems ill-suited to “outside expert” research
- History of research abuse and mistrust
- Disappointing results in intervention research
- Interest in research to improve best practices/processes



---

---

---

---

---


---

---

---

### CBPR Role in Reducing Health Disparities

- Communities most affected by health disparities
- Develop partnerships with trusted community members
- Identify assets of community to improve health outcomes and reduce disparities
- Mobilize community resources towards targeting health disparities
- Tailor outcomes to specific community needs




---

---

---

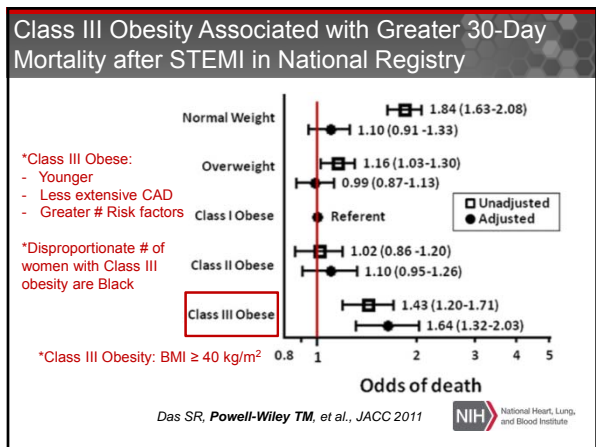
---

---

---

---

---




---

---

---

---

---

---


---

---

### Obesity is a Target to Improve Cardiovascular Health

- CV Health Factors
  - Physical Activity
  - Dietary Intake
  - **Body Mass Index**
  - Total Cholesterol
  - Fasting Glucose
  - Blood Pressure
  - Cigarette Smoking
- CV Health Factors can be ideal, intermediate or poor
- Those in U.S. with poor CV health less likely to have health care access

Dong C. et al., Circulation 2010;  
McClurkin M., Yingling L. et al. Powell-Wiley TM, PLOS One 2015




---

---

---

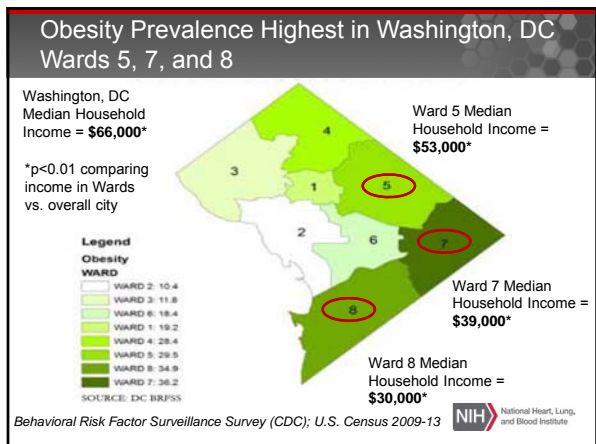
---

---

---

---

---




---

---

---

---

---

---

---

---

---

---

### Key Principles of Community Engagement in CBPR

- Be clear about purposes/goals of effort
- Become knowledgeable about community
- Go into community and build trust/seek commitment among formal and informal leadership

NIH National Heart, Lung, and Blood Institute

---

---

---

---

---

---

---

---

---

---

### Key Principles of Community Engagement in CBPR

- Accept that self-determination is right responsibility of all people who constitute community
- Partner to create change and improve health
- Recognize and respect community diversity

NIH National Heart, Lung, and Blood Institute

---

---

---

---

---

---

---



---

---

---

### Key Principles of Community Engagement in CBPR

- Identify and mobilize community assets
- Release control of actions/interventions to community; be flexible to meet changing community needs
- Requires long-term process and commitment



---

---

---

---

---

---


---

---

### Guiding Principles/Core Values of CBPR

▪ Trust	▪ Full participation
▪ Respect	▪ Reciprocity
▪ Self-determination	▪ Collective benefit
▪ Mutuality of interests	▪ Long-term commitment
▪ Perspective taking	

Manson SM et al., J of Aging Health 2004;  
Norton IM et al., J of Consult Clinical Psych 1996



---

---

---

---

---


---

---

---

### CBPR: What it is and isn't

- CBPR **is an approach** to research
  - changes the role of researcher/agency and researched
- CBPR is **not** a specific method or set of methods
  - Can involve qualitative and quantitative methods
  - Can involve multiple research designs (observational studies and/or randomized trials)
- CBPR goal is to influence change in community health, norms, systems, programs/policies



---

---

---

---

---


---

---

---

### Application of CBPR Approach

1. Descriptive research to identify multiple determinants of health	2. Research to understand disparities in health status and health-related risk
<p>CBPR is particularly applicable to four types of research.</p>	
3. Research to understand community needs, problems, resources and assets	4. Efforts to design, implement, and evaluate interventions and policies




---

---

---

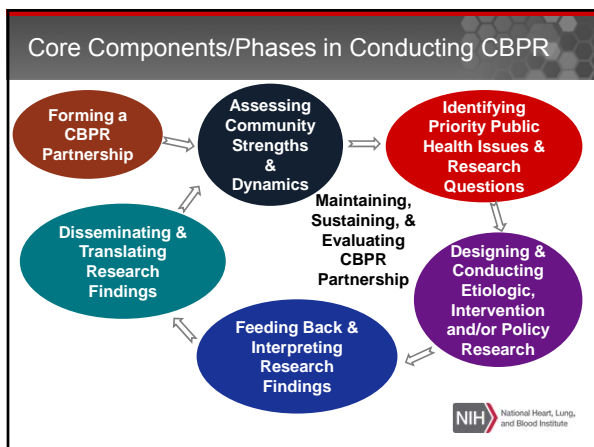
---

---

---

---

---




---

---

---

---

---

---

---

---

### CBPR Step 1: Building Partnerships

- Self-Reflection
  - Intentions, capacities, and liabilities
  - Our institution's strengths and liabilities
- Identify Potential Partners
- Negotiate Targets for Work
- Create and Build Participatory Structures between:
  - Academia and Community
  - Principles
  - Decision-making
  - Control of budgets and data




---

---

---

---

---

---

---

---

Building CBPR Partnerships: Powell-Wiley Group

- Self-Reflection
  - Honest about focus on CV health
  - Strengths in identifying novel methods for intervention (i.e. mobile health technology)
- Identify Potential Partners
  - One-on-one meetings with community leaders
  - Presentations to government, advisory neighborhood commissions (ANCs), public health organizations, academia, churches
- Required about 1.5 years of work




---

---

---

---

---

---

---

---

Community Advisory Board – DC Cardiovascular Health and Obesity Collaborative (DC CHOC)

Faith-Based Organizations	Academia/Health Care Organizations
St. John CME Church	Howard University
New Samaritan Baptist Church	Howard University School of Medicine
Penn Avenue Baptist Church	Wesley Theological Seminary
Plymouth Congregational Church	Georgetown University
Non-Profit Organizations	Community Representatives
Advocates for Black Communities	Ward 5
American Heart Association	Ward 7
	Ward 8
Local/Federal Government	
D.C. Department of Health	
U.S. Department of Agriculture	
National Institutes of Health	

▪ Hold quarterly meetings  
 ▪ Provides feedback on research design and implementation

NIH Protocol # 13-H-0183 – PI: Powell-Wiley




---

---

---

---

---

---

---

---

CBPR Step 2: Identify Research Questions and Methods

- Difference between community outreach and CBPR
- Where do questions come from: community or academia or both?
- Initial participation by Advisory Committee?
- Continual participation throughout which informs and changes intervention?




---

---

---

---

---


---

---

---

**CBPR Step 3: Participatory Data Collection**

- Participatory process that is most used
- Train community interviewers, survey data collectors, focus group facilitators
- Job opportunities for community
- Enables better response rate
- Issues of confidentiality



---

---

---

---

---

---


---

---

**Hypothesis for Powell-Wiley Research Group**

- A CBPR approach, including mixed methods (qualitative and quantitative) approaches, would engage community members in Washington, DC to use mobile health technology targeting physical activity and dietary intake as CV health factors.

NIH Protocol # 13-H-0183 – PI: **Powell-Wiley**



---

---

---

---

---

---

---

---

**Clinical Protocol Summary**

---


**Protocol Title** Cardiovascular Health and Needs Assessment in Washington D.C. - Development of a Community-Based Behavioral Weight Loss Intervention

**Collaborating Centers** Howard University, Washington D.C.

**Type** Observational Study

---

NIH Protocol # 13-H-0183 – PI: **Powell-Wiley**



---

---

---

---

---

---

---

---



### Clinical Protocol Summary

**Primary Endpoint** Prevalence of ideal, intermediate, and poor levels of CV health factors in a sample population from predominantly African-American faith-based organizations in Wards 5, 7, and 8 of Washington D.C.

- Secondary Endpoints**
- Physical activity (PA) levels measured by a PA wristband vs. PA measured by survey or accelerometer
  - Feasibility of a handheld, digital camera to take photographs of dietary intake
  - Evaluation of usage of web-based technology for monitoring CV health
  - PA and dietary intake across levels of psychosocial factors, cultural norms, and neighborhood environment factors

NIH Protocol # 13-H-0183 – PI: **Powell-Wiley**



---

---

---

---

---

---

---

---

### Mixed-Methods Approach to CBPR

- Focus Groups
  - Recommended by DC CHOC members
  - Done in collaboration with Wallen Group, NIH CC
- Goals of Focus Groups
  - Focus Group #1: Group-based cognitive interviewing for refining the survey instrument
  - Focus Group #2: Barriers to use of technological tools (wrist-worn PA monitor, digital food record)

NIH Protocol # 13-H-0183 – PI: **Powell-Wiley**



---

---

---

---

---

---

---

---

### Qualitative Data From Group-Based Cognitive Interview Led to Survey Modifications

- Changes made to the survey based on participants' suggestions included:
  - reformatting physical activity (PA), diet and weight history scales and responses
  - inclusion of more culturally relevant, community-specific questions related to self-efficacy and health behaviors

Saygbe J et al., **Powell-Wiley TM** – In Preparation



---

---

---

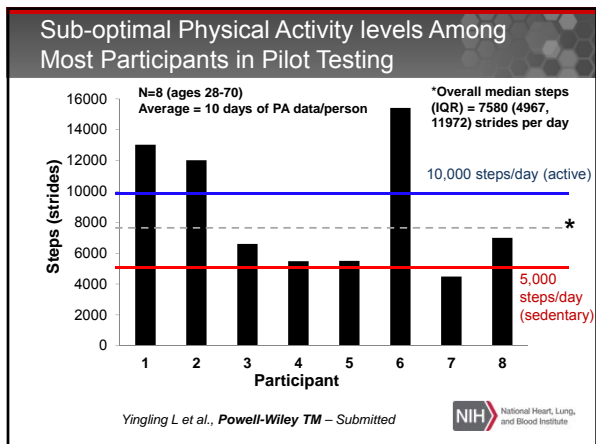
---

---

---

---

---




---

---

---

---

---

---

---

---

---

---

- ### Hypothesis: Community members would be willing to use PA wristbands for activity self-monitoring.
- One hub per church used to address:
- Socioeconomic and geographic barriers to broadband network and wi-Fi access
  - Limited access to computers
  - Restricted smartphone data plans for use of mHealth devices
  - Limited technology literacy
- Yingling L et al., Powell-Wiley TM – JMIR mHealth and uHealth 2016*

---

---

---

---

---

---

---

---

---

---

### Data Collection Logistics

<b>Station 1:</b> Participant Registration	<b>Station 2:</b> • Blood Testing • Blood Pressure Measurement • Body Size Measurement	<b>Station 3:</b> Survey Assessment	<b>Station 4:</b> Device Training	<b>Station 5:</b> Review of Results with Dr. Powell-Wiley
---	---	--	--------------------------------------	--

- Up to 25 participants for each data collection event
- Six data collection events over four church sites
- At each site, community expert in using PA system

*NIH Protocol # 13-H-0183 – PI: Powell-Wiley*

---

---

---

---

---

---

---

---

---

---

### CBPR Step 4: Participatory Data Analysis

- Role of University expertise:
  - Statistical programs (Quantitative/Qualitative)
  - Present data in useable form for interpretation
  - Train community members
- Role of Community expertise:
  - Provide interpretation of importance that only possible if from locality (local research team/advisory committee)
  - Protection of community




---

---

---

---

---

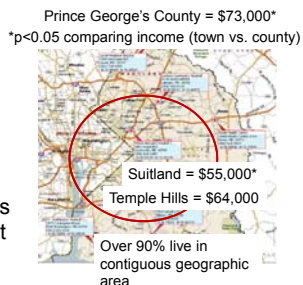
---

---

---

### Enrolled Population from Contiguous Geographic Area

- 100 participants
  - 79% women
  - 99% African American
- 48% D.C. residents
  - 80% from Wards 5, 7, 8
- 44% from Prince George's County (adjacent to target D.C. wards)



NIH Protocol # 13-H-0183 – PI: Powell-Wiley




---

---

---

---

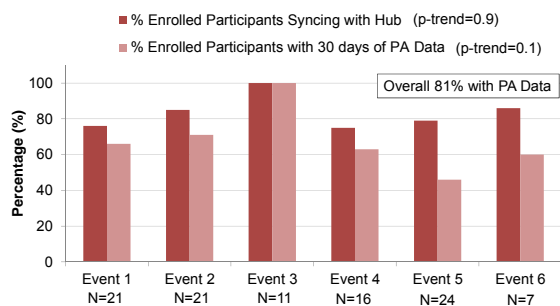
---

---

---

---

### Use of PA Monitoring System in Community Appears Feasible



NIH Protocol # 13-H-0183 – PI: Powell-Wiley




---

---

---

---

---

---

---


---

### PA Monitor Users are of lower SES than PA Monitor Non-Users

Characteristics	Users (N=81)	Non-Users (N=19)	P-value
Age, years (SD)*	60 (12)	57 (13)	0.4
African American race (%)	99%	100%	0.5
Male (%)	22%	16%	0.5
<b>Household Income &lt;\$60,000</b>	<b>51%</b>	<b>27%</b>	<b>0.01</b>
Employed (%)	46%	56%	0.1
Married (%)	48%	29%	0.3
Some College Education (%)	76%	83%	0.4
Has Health Insurance (%)	98%	100%	0.5
Body Mass Index, kg/m <sup>2</sup> (SD)*	32 (7)	35 (7)	0.08

\*mean value with standard deviation

NIH Protocol # 13-H-0183 – PI: Powell-Wiley




---

---

---

---

---

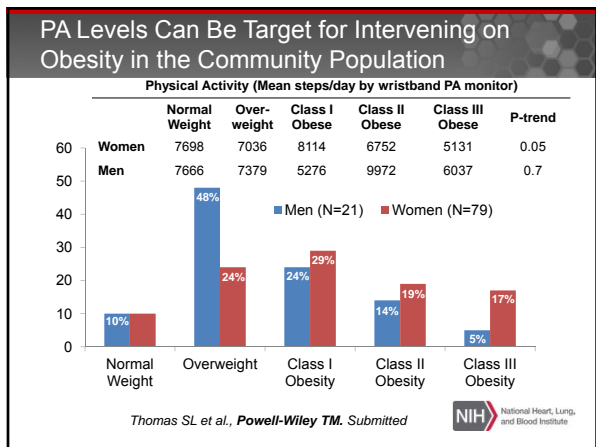
---

---

---

---

---




---

---

---

---

---


---

---

---

---

---

- ### CBPR Step 5: Participatory Dissemination
- Accountability to communities and to community protection
  - Community reports (print/videos/etc)
  - Academic publishing issues (especially for junior faculty)
- Wallerstein, N., Duran, B., Minkler, M., Foley, K., Developing and Maintaining Partnerships, *Methods in Community Based Participatory Research*, Israel, B., et al (eds). San Francisco, Jossey Bass, 2005
- 

---

---

---

---

---

---

---

---

---

---

### Dissemination Efforts: Powell-Wiley Group

- Early dissemination of focus group data
- Evaluated community organization for dissemination
- Identified preferred methods for data dissemination to community
- Data briefs and newsletters for partnering churches and community advisory board
- Presentations in community
- Abstracts and publications



---

---

---

---

---

---

---

---

### Challenges in Researcher-Community Relationships

- Nuances of participation and community consent (who is participating/who is not)
- Power and privilege: Who sets the research question? Who has power of knowledge?
- Historical research abuse/stereotyping/racism
- Be willing to face the reality of negative history



---

---

---

---

---

---

---

---

### Challenges in Researcher-Community relationships

- Academic vs. community time: publishing versus taking action
- CBPR cyclical and iterative process: research goals are not always known at the beginning of work
- Research team having necessary skills, ie., cultural humility, listening, sharing decision-making



---

---

---

---

---


---

---

---

**Benefits of CBPR**

- Enhances relevance of research questions to the communities at highest risk
- Enhances reliability and validity of measurement instruments
- Improves response rates
- Enhances recruitment and retention
- Strengthens intervention by incorporating cultural beliefs into scientifically valid approaches



---

---

---

---

---


---

---

---

**Benefits of CBPR**

- Increases accurate and culturally sensitive interpretation of findings
- Facilitates effective dissemination of findings to impact public health and policy
- Increases translation of evidence-based research into sustainable community change
- Increases research trust
- Provides resources and benefits to communities
- Joins partners with diverse expertise



---

---

---

---

---


---

---

---

**Future Directions: CBPR in Powell-Wiley Group**

- Increase community members' involvement with community advisory board
- Development of new methods for dissemination
- Intervention targeting physical activity
  - Use of mobile health technology
  - Tailored messaging to neighborhood resources
  - Focus on Wards 5, 7, 8 and Prince George's County



---

---

---

---

---

---

---

---

### Acknowledgements

- Dr. Francisco Sy, MD, MPH, NIMHD
- Dr. Barbara Israel, University of Michigan
- Dr. Nina Wallerstein, University of New Mexico
- Dr. Keawe Kohulokula, University of Hawaii
- Study Participants
- Powell-Wiley Research Group
- Associate Investigators on Protocols 13-H-N041 and 13-H-0183
- Howard University
- Faith-based Organizations
- Members of DC Cardiovascular Health and Obesity Collaborative



---

---

---

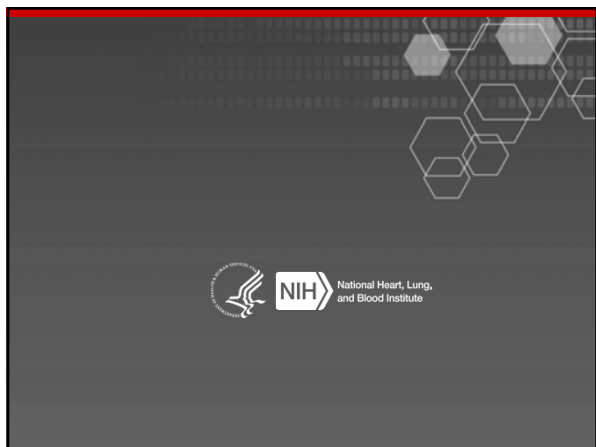
---

---

---

---

---



---

---

---

---

---

---

---

---