NYU Langone Health
Office of Science and Research
Clinical and Translational Science Institute
Integrating Special Populations Core
Engaging Special Populations Best Practice Brief
Black, African American Population
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Integrating Special Populations

Overview

Demographic Profile

New York has the fourth largest population of Black (i.e. African, African American, Afro-Caribbean, or any ethnicity of African descent) persons among all 50 states. In NYC, the Black community represents the third largest racial ethnic group, comprising of almost 22% of the population (~1.9 million) [see Figure 1]. One quarter of the Black population is comprised of African and Afro-Caribbean, non-Hispanic foreign-born immigrants. The foreign-born Black population is 5% of the overall immigrant population in NYC, but despite its small percentage the Black immigrant population faces its own set of health disparities. For example, immigrant families comprise a large majority of the uninsured and low-income populations in NYC and experience challenges related to access to care, health literacy levels, limited English proficiency).

Race and Ethnicity	Estimate	Percent
Total population	8,622,698	
Hispanic or Latino/a (of any race)	2,517,429	29.2%
White alone	2,733,369	31.7%
Black or African American alone	1,879,876	21.8%
American Indian and Alaska Native alone	13,835	0.2%
Asian alone	1,241,650	14.4%
Native Hawaiian and other Pacific Islander alone	2,119	0.0%
Some other race alone	77,127	0.9%
Two or more races	157,293	1.8%

Figure 1. Race and Ethnicity in NYC, 2017.3

Black Population in NYC Black people make up 22% of the NYC population² 60% of Black people live in either Brooklyn or Bronx³ 18.7% live below the poverty line⁴ Over 75% are U.S. born and less than 25% are foreign born⁵ 5% of foreign-born NYC residents are from Africa alone⁵

Figure 2. The Black population is comprised of different diverse groups.

Health Profile

The Black community has some of the poorest health outcomes and lower overall life expectancy (highest years of life lost) compared to non-Hispanic Whites across NYC and the US.^{1,5} Black people have the highest prevalence rates and mortality rates for obesity, high blood pressure, heart disease, cancer, stroke and diabetes.⁵ Black, non-Hispanic patients have the highest mortality rates, hospitalization rates, premature birth rates, low birthweights births, infant mortality rates, maternal mortality rates, and asthma and chronic lower respiratory hospitalization rates across all demographics in NYC.⁵ Additionally, Black people have higher disease prevalence compared to White and overall NYC residents.⁵ According to the US Department of Health and Human Service's Office of Minority Health, the national death rate for Black persons is generally higher than White persons for heart diseases, stroke, cancer, asthma, influenza and pneumonia, diabetes, HIV/AIDS, and homicide.¹





Black/ AA Engagement in Research

Community engaged research is the process of addressing issues affecting the target populations of a study by collaborating and involving those directly impacted by studies in the research process⁷. The extent to which a research study requires community involvement will vary depending on the needs of the study. Thus, community engaged research exists on a spectrum (as seen in Figure 3). For a community-engaged study that moves further to the right on the spectrum, there is greater community involvement with a stronger bidirectional relationship and shared leadership between researchers and the community⁸. Community-based participatory research (CBPR) studies are research studies formatted to incorporate community members into the research process.⁶ The CBPR approach has shown much success in conducting research within disenfranchised communities since community engaged research facilitates trust and effective communication, which can later lead to community buy-in and future study sustainability.⁶

Community Engagement Continuum Increasing Level of Community Involvement, Impact, Trust, and Communication Flow Outreach Consult Involve Collaborate Shared Leadership Some Community More Community Better Community Community Involvement Strong Bidirectional Communication flow is Communication flows Communication flows to Communication flows Final decision making is from one to the other, to at community level. the community and then both ways, participatory Forms partnerships with back, answer seeking form of communication Entities have formed community on each Gets information or feedaspect of project from development to solution. Provides community with Involves more participastrong partnership back from the community. tion with community on information Entities share information Entities form bidirectional Outcomes: Broader Entities coexist. Entities cooperate with health outcomes affectcommunication channels Outcomes: Develops con-Outcomes: Optimally, each other. ing broader community. Strong bidirectional trust built. nections. Outcomes: Partnership establishes communica-Outcomes: Visibility of building, trust building. tion channels and chanpartnership established with increased cooperanels for outreach Reference: Modified by the authors from the International Association for Public Participation.

Figure 3. As study moves further to the right on the spectrum, the greater bidirectional relationship and shared leadership between researchers and the community. Source: Principles of Community Engagement Report (2nd Ed.), Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee Task Force on the Principles of Community Engagement.

Best Practices in Engaging the Black/AA Community

When specifically addressing the Black community, there are several considerations researchers must take to successfully develop long-term, amiable relationships:

- Warm, interpersonal relationships with the community helps combat stigma and distrust of academic institutions⁸
- Emphasis on affiliation and cooperation of the community is a pertinent cultural value that has been shown to help increase engagement of the Black community⁹
- Researchers must acknowledge the fact that implicit bias, uninformed/unconsented experimentation, and systemic racism have all played a large role in mistrust between the medical/research and Black communities.^{10,11}







Recruitment Best Practices

Outreach

- Promote and advertise the research study in a culturally and linguistically appropriate way¹²
- Utilize Black research coordinators and/or other BIPOC research staff members who can help ensure better communication with community members ¹²
- Disaggregate Black data from national data, then use localized data, community needs assessments and community surveys to determine needs and areas of investigation¹²
- Establish community relationships with community leaders or stakeholders (e.g., partner with community healthcare providers, faith-based leaders, community health workers, patient navigators, social & community service agency directors)¹²
- Create a community advisory board or panel to get direct study/project feedback, outreach ideas, and dissemination assistance¹²
- Attend and participate in neighborhood events to engage with and establish a strong relationship with families and encourage families to recruit their family members¹²
- Emphasize the importance of the work and the need for community involvement so families feel invested in the project and sustain research practices after study completion¹²
- Consider how the social determinants of health (i.e. physical and social barriers to health equity) affect participation, such as taking time away from work, traveling to a university or hospital setting for data collection, etc. ¹²

Scheduling and Costs

- Incorporate flexible data collection schedules in your protocol¹²
- Provide support services that would help offset participant costs (e.g., childcare, food, public transportation or rideshare vouchers, parking validation)¹²
- Conduct data collection in flexible locations (e.g., faith-based centers, community centers, recreation centers, local clinics, schools)¹²
- Provide fair and culturally appropriate compensation for participation (consult community members or advisory board and use recommended form of compensation)¹²

Education and Language

- Provide community workshops or trainings about adverse effects and participant liability in clinical trials¹³
- Be aware of health literacy levels when communicating by using plain language (7th grade reading level) or using jargon-free language¹³
- Provide options for participants to complete study measures independently or with the help of a research assistant¹³
- Provide options for study measures to be administered verbally¹³

Cultural Sensitivity and Values

- Critically examine questions and assess whether certain questions may be alienating and only include necessary demographic questions (e.g., sensitivity to questions about education levels, addiction, housing, or income)^{15,16,17}
- Consider cultural norms and values (e.g., mistrust of medical system and personnel) and be conscious of any implicit bias or stereotypes when designing the study protocol 15,16,17
- Address participants with appropriate and culturally relevant language to indicate mutual respect 15,16,17
- Be mindful of differences in social and cultural practices (e.g., individualism versus collectivism framing) and communication styles in developing recruitment materials and messages. 15,16,17







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Integrating Special Populations

Internal & External Resources

Research and Recruitment Resources	NYULH Trainings &	Health Profiles	National Organizations
	Resources*		
Lessons learned for recruitment and	CDC Plain Language	Black/African American	Black Mama's Matter
retention of low-income African		Population Profile (US	Alliance (Black Maternal
Americans (ePub journal article)		Office of Minority Health	Health Organization)
•		<u>report)</u>	
Strategies Addressing Barriers to Clinical	CDC Health Literacy	NYC Health Indicators by	Society for the Analysis of
Trial Enrollment of Underrepresented	-	Race (NY State Dept. of	African American Public
Populations (ePub journal article)		Health report)	Health Issues (SAAPHI)
Recruitment of Black Identifying Young	CDC Select Terms for	African American Health	Black Women for Wellness
Adults into Clinical Trials: COVID-19	<u>Populations</u>	Vital Signs Report (CDC	(BWWLA)
(ePub journal article)		<u>report)</u>	
A Model to Translate Evidence-Based	FOCUS Inclusive Mindset	Health Disparities by Race	Black Women's Health
Interventions Into Community Practice	Training	and Ethnicity (Center for	Imperative (BWHI)
(ePub journal article)	_	<u>American Progress report)</u>	
Development of "Advancing People of	FOCUS Driving Change and	Health Disparities Among	Mamatoto Village (Healthy
Color in Clinical Trials Now!": Web-	Anti-Racism Training	African-Americans (Pfizer	Mamas + Babies +
Based Randomized Controlled Trial	_	<u>report)</u>	Communities Initiative)
Protocol (ePub journal article)			
Top Black Health Resources List (Black	FOCUS Supporting Allyship	Race and health profiles in	The Love Land Foundation
News resource)	and Anti-Racism at Work	the US: CHIS adult survey	(Support for Black women
	Training	(ePub journal article)	and girls)
List of U.S. Minority Organizations (US	FOCUS Discussing Racism	Improving the health of	National Institute on
Office of Minority Health resource)	Training	African Americans in the	Minority Health and Health
		USA: an overdue	Disparities (NIMHD)
		opportunity for social	
		justice (ePub journal article)	
Accrual of Black participants to cancer	FOCUS How to Speak Up	Race, Ethnicity, and	African American
clinical trials following community	Against Racism at Work	<u>Language Data:</u>	Community Health Advisory
outreach and engagement (ePub journal	Training	Standardization for Health	Committee (AACHAC)
article)		Care Quality Improvement	
		(Agency for Healthcare	
		Research and Quality	
		report)	
Minority Recruitment Websites (U of Tex	FOCUS Design Thinking,	Health Disparities	African American Health
San Ant, Long School of Med resource)	Social Innovation, and	Experienced by Black or	Program (Montgomery
	Complex Systems Training	African Americans (CDC	County Dept. of HHS)
		report)	
Engaging African Americans in	FOCUS Just Ask: Discussing	Black and African American	Cross Cultural Health Care
Research: The Recruiter's Perspective	Race Training	Health (Medline Plus report)	Program (XCulture)
(ePub journal article)			
Michigan Center for Urban African	FOCUS Building Inclusive	Racism, Inequality, and	The Center for African
American Aging Research Participant	Work Communities Training	Health Care for African	American Health (CAAH)
Resource Pool (MCUAAAR resource)		Americans Report (The	
		Century Foundation report)	
Recruitment of Black Adults into	FOCUS Strategies to Foster		Association of Clinicians for
Cardiovascular Disease Trials (ePub	Inclusive Language Training		the Underserved (ACU -
<u>journal article)</u>			<u>Clinicians)</u>





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Research and Recruitment Resources	NYULH Trainings & Resources*	Health Profiles	National Organizations
Best strategies to recruit and enroll elderly Blacks into clinical and biomedical research (ePub journal article)	FOCUS Strategic Resources and Support Services for Investigators & Study Teams FOCUS Talking About Race at Work Training		
	FOCUS Marketing to Diverse Audiences Training FOCUS Creating a Culture of Collaboration Training		
	FOCUS Communicating Across Cultures Training		
	FOCUS Best Practices for Managing Projects Across Cultures Training		
	FOCUS Cultural Competency at NYULH Training		
	FOCUS Interpersonal Communication Training		
	FOCUS Managing a Diverse Team Training		
	FOCUS Diversity, Inclusion and Belonging Training		
	FOCUS Inclusivity in Committed Allies Training		
	FOCUS Leading Inclusive Teams Training		
	FOCUS Confronting Bias: Thriving Across Our Differences Training		
	FOCUS Addressing Unconscious Bias in Medicine Training		

*FOCUS only accessible with Kerberos ID.



